# Aboriginal Female Sexual Health in a Context of Cervical Cancer and Cervical Cytology Screening With Reference to the Cree and Cree-Métis of Northern Alberta

by

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# Abstract

Trapped within 'deficit model' methodologies, pathologizing views of Aboriginal women, their sexual health, and overall health proliferate in health research and literature, perpetuating a tendency to view these populations through a 'singular negative orientation'. Cervical cancer research, in particular, concentrates on cervical cytology screening and identifies Indigenous women as the one homogenous group predominantly lacking in knowledge or possessing inaccurate knowledge of the behaviours that lead to the early detection of cervical cancer.

This research involved Northern Alberta self-identifying Cree and Cree-Métis women who have experienced cervical cancer and self-identifying Cree and Cree-Métis Elders recognized within their various Aboriginal communities as having expert knowledge of their cultures, traditional norms, and teachings. Findings suggest that the women's experiences with cervical cancer induced feelings of fear, pain, and frustration. These feelings were related to the development of the illness, its progression, and the care that the women received with regards to associated treatments and procedures, the lack of information they were given, and a lack of understanding regarding the disease, its diagnoses, and treatments. Additionally, cervical cancer was a single illness affecting the women's lives, while their stories revealed that they draw upon traditional knowledge and teachings in relation to their sexual and overall health.

The research process was developed and carried out within an Indigenous research framework, adhering to Cree and Métis protocols of relationships and communication. The purpose was to gain new insights about how culturally informed knowledge influences and supports the sexual health of Aboriginal women, particularly in relation to cervical cancer and cervical cytology screening. Several key Indigenous principles of research – respect, reciprocity, relationship building – guided this research process and are shown to underlay successful outcomes of working with Cree and Cree-Métis women, Elders, and communities. The research process and the learning were shown to evolve in a spiral pattern, expanding outwards as the stories of the women and the teachings of the Elders built upon one another to create new images and insights into the sexual health and wellness of this particular group of Aboriginal women.

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# REFLECTION OF RESEARCH PERSPECTIVES & PATHWAYS

> *...the consciousness that solves a problem can no longer be the consciousness that created it. The same is true for Indigenous research. We are trying to articulate a new/ancient consciousness that is no longer interested in why Hawaiian youth don't score as well as their American counterparts on the SAT.* ***That is not our question****. It is, rather, a matter of reinterpretation–of redefining the things of value with regard to knowledge and how we wish to live our lives. We have choices here. (Meyer, 2003, p. 251)*

The perspectives upon which this research was built reflect historical, political, social, and cultural worldviews that shape and affect the lives and experiences of Cree and Cree-Métis women, Elders, and communities across Northern Alberta. As an Indigenous researcher working and living from within this same historical and social context, this research brought me to a fuller understanding and deeper appreciation of the significance of culture and language for the health and wellness of Aboriginal women in general, and specifically these Aboriginal women of Northern Alberta. Through efforts to articulate appropriately and clearly the culturally significant and deep layers of meaning that were embedded in the stories and in the different aspects of the research process itself, I came to understand that describing the various contexts of the research was as important as identifying the research findings and discussing their broader implications. As has been pointed out by other Indigenous researchers, including Meyer (2003), the findings of my research naturally and necessarily revealed their deeper meanings from within contexts and worldview(s) that are dissimilar to those of many of the people who will or who may read the work. In this introduction, I will share the intentions and anticipated outcomes with which I began this work, and I will lay out the paths of my journey through this work in order to support readers' understanding of the perspectives within which the research experience unfolded.

My interest in cervical cancer and cervical cytology screening with Aboriginal women began during a Masters program in Community and Public Health Nursing. I was working on a project with the Alberta Cancer Board and the Yellowhead Tribal Council of Alberta, a regional council consisting of five First Nations communities. The work included several focus groups, individual telephone interviews, and ongoing discussions with specific Aboriginal health representatives belonging to the regional council and community members from the five First Nations to identify factors important for the development of an Aboriginal Cancer Control Strategy[1]. The Aboriginal Liaison person guided the project to a focus on cervical cancer and cervical cytology screening. During my involvement with this work, I began to feel uncertain that increasing community awareness about cancer and cancer screening would lead to any actual improvements in cancer screening participation or early cancer diagnoses.

This uncertainty was based on the following observations. First, I was aware from my own personal contacts across many tribal groups and communities that Aboriginal people, generally, are tired of being asked questions by researchers and that often they see no real advantage to them or their community in providing more information to researchers. Second, I had come to realize that most of the information being requested from Aboriginal peoples by health researchers was aimed at increasing the knowledge bank of western medicine and western health care practices. At the same time, such research reflected no recognition of the traditional Aboriginal norms, teachings, and practices that form the bases of health and vitality for these peoples and their communities. Third, one desired outcome of health research is to provide health information to Aboriginal peoples and thereby affect their decisions in relation to their own health and health service delivery. Of significance here is that the information to be provided is identified and disseminated according to methods and processes that are based upon a Western scientific perspective[2]. In relation to cancer and cancer screening, Western research is often carried out with the assumption that Aboriginal community members are either uninformed or misinformed about these topics. In this research project with the Alberta Cancer Board and the Yellowhead Tribal Council, little attempt was made to identify or understand the health knowledge that community members did possess; such knowledge was viewed as incongruent or irrelevant to the goals and outcomes of the project.

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[1] The "Aboriginal Cancer Control Strategy" was developed by the Alberta Cancer Board in 2002. This document is currently being used to produce education and programming specific to cancer and cancer care for Aboriginal peoples within Alberta.

[2] Western within this research refers to those Canadian and 'American' ideas and practices, including colonialism, that emanated originally from European modes of thought or ways to view the world and is used here synonymously with 'mainstream'.

During the next several years, two persons, a close friend and a family member died from cervical cancer and I began to wonder if and why these women had avoided cervical cytology screening (more commonly known as the Pap test). As a nurse, I understood that participation in cervical cytology screening could lead to an early diagnosis and successful treatment of the disease. However, through conversations with these women before they died, I discovered that feelings of apprehension and fear contributed to the actions (or inactions) of these women. The actions (or inactions), for these women, seemed related to their fears of being judged by others, including health care service providers, regarding a sexual health concern. They also spoke about a fear of derision, which they felt stemmed from the fact that they possessed different views of health than those of the health professionals. For example, from a western perspective, the failure of these women to access the public health care system in a timely manner was viewed as inaction that led to a diagnosis and treatment of the disease after it was too late.

I later came to understand from the Aboriginal women who participated in my study that cervical cancer was associated with a less than perfect lifestyle, or even promiscuous, lifestyle. In many Aboriginal communities across Canada, where historical events such as the Residential School Legacy[3] have left untold damage through enforced assimilation and sexual abuse, this association between cervical cancer and sexual behaviour has worked to reinforce feelings of trepidation and fear in Aboriginal women. Acutely aware that they are already marginalized within Canadian society, the research participants who shared their stories expressed a common fear in speaking about cervical cancer: western medicine is too eager to label cervical cancer an Aboriginal woman's disease.

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[3] From the mid 1800's to the last residential school closure in 1967, many Aboriginal children were removed from their homes and forced into a system designed to remove cultural identities and instill western ideals.

As my interest in the area of cervical cancer research grew, I began to look for research and literature that addressed cervical cancer in relation to Aboriginal women. I found that available research and literature revealed recurring themes of an overwhelming focus on the prevalence of risk factors for the development of cervical cancer among Aboriginal populations and the lack of participation by these same populations in screening. Aboriginal women's sexual health was often oversimplified, scrutinized, and categorized according to 'poor' health status and a tendency to participate in 'risk-taking' behaviours (Bennett, 2005; Dion Stout & Kipling, 1998; Elias, 2003). These approaches to sexual and reproductive health research with Aboriginal/Indigenous women, most often sought explanations for reports of escalated prevalence of risk factors for ill sexual health, such as cervical cancer, and the decreased screening participation of Aboriginal/Indigenous women across the globe (Alberta Health & Wellness, 2004; Bottorff *et al.*, 2005; Johnston *et al.*, 2005; Population Reference Bureau, 2004; World Health Organization, 2002).

Over the next couple of years, I became less and less accepting of what I was perceiving as negative and degrading biases towards Aboriginal women in sexual health research and literature. With few exceptions, Aboriginal women were portrayed as deficient, either lacking in their knowledge of positive health behaviours and/or as neglectful of their own sexual health. Moreover, Aboriginal women were often reported to have little awareness or understanding of sexual health and wellness. Although there were theories that suggested explanations and reasons for this lack of awareness, I realised that these theories ignored or demonstrated only a limited understanding of the knowledge that Aboriginal women do possess and how this knowledge informs their health decisions. As an Aboriginal woman, with a large extended family and community, I already knew that my sisters, aunties, and grandmothers were more aware of their sexual health than the research and the literature were suggesting. With such primary and empirical data at my fingertips, I wondered exactly what was the knowledge that these women had and simultaneously I recognised a significant gap in the health research and literature that pertained to Aboriginal women's sexual health and overall health.

While a limited amount of health research was beginning to acknowledge such a gap, even less research was seeking to locate Aboriginal women outside the 'pathologizing' framework. In fact, existing health research on Aboriginal women displayed such an overwhelming tendency to focus on 'deficiencies' that Indigenous scholars and researchers had begun to argue that the majority of health research falls within two frameworks – those that are 'problem-focused' or those that utilize a 'singular negative orientation' (Bennett, 2005; Dion Stout and Kipling, 1998; Elias, 2003; Ermine *et al.*, 2004).

My own work, through the women's stories, would demonstrate that these Aboriginal women associated cervical cancer with a less-than-perfect lifestyle or even promiscuous lifestyle and this point would have been substantiated, it seems, within the 'negative orientation' research. An excellent example of the 'negative orientation' in the literature was the 'fatalistic attitude' that was being cited as common among Indigenous peoples in relation to cancer diagnoses and treatments and to Aboriginal women in particular relation to cervical cancer diagnoses and treatments (Hart-Wasekeesikaw, 1996; Kaur, 1996; McMichael *et al.*, 2000; Roberts, 2005).

Culturally specific information and perspectives on Aboriginal female sexual health were nonexistent within the relevant research and literature. This resounding absence of Aboriginal women's voices within a potentially stigmatizing and particularly intimate area of health research, cervical cancer and cervical cytology screening, became a source of angst for me as it raised many questions regarding the health care delivery system's views and treatment of Aboriginal women. My frustrations and concern were further compounded by the fact that I had worked for several years as a Registered Nurse within acute care facilities that served the North and as a student of health research within Northern Alberta Cree and Cree-Métis communities. On many occasions, I had witnessed first hand the inabilities of health care service providers to acknowledge Aboriginal women's views and concerns, much less understand and address them. For these reasons, the primary motivation for this work was the need to hear the voices of Aboriginal women in relation to their own sexual health. In the context of stories shared by several Cree and Cree-Métis women, and as a significant part of the interpretation and validation aspects of the data, it was also important for me to articulate, within personal and cultural limitations, the wisdom of traditional teachings provided by a group of Cree and Métis women Elders who served as advisors to my learning process during this journey.

As I moved into my own research focus and literature review, I noted that current research and literature raised or pointed to many of the challenges that I would experience in conducting this research. Most of the literature, for example, lacked a comprehensive and meaningful understanding of the volatile nature of the historical, economic, and socio-political environments in which many Aboriginal women of Canada are forced to survive. As well, the literature brought forth little insight into the significance of Aboriginal cultural teachings, norms, and practices on the sexual health of Aboriginal women. This was particularly evidenced by the absence and failure of most health research to address or include Aboriginal perspectives of health, even those most commonly held up as almost universal among Indigenous and/or Aboriginal peoples, such as holism: the perspective that health and wellness must focus on more than the physical aspect and manifestations of an illness or disease. Finally, the literature tended to intensify the stigmatizing nature of a sexual and reproductive illness experience for Aboriginal women through the perpetuation of current pathologizing views and negative stereotypes.

These limiting factors and the restrictive nature of current health research led me to develop a project that focused on the ‘re-discovery’ of the knowledge that Aboriginal women do possess and how this knowledge informs and supports their own health and wellness. Working towards this end held its own specific challenges. These challenges were primarily process-oriented and included: the liberation of Aboriginal women and the location of the discourse around their sexual health to outside the pathology discourse; working in culturally appropriate ways with Aboriginal women, Elders, and communities while meeting the requirements of a western intellectual institution; and describing and articulating traditional cultural teachings and knowledge from a particular Aboriginal group.

Moving away from the pathology discourse is representative of the new jargon in relation to health research with 'disadvantaged' social or ethnic groups, including Aboriginal women and their communities. In fact, recent work about research with Aboriginal peoples talks about reframing the contexts of such research outside the 'resistance language' (Anderson, 2000; Bennett, 2005; Ermine *et al.*, 2004; Graveline, 1998). This includes the work of Indigenous scholars and researchers such as Anderson (2000) who talks about resisting negative images of Aboriginal women through reclaiming the cultural knowledge and teachings of Aboriginal peoples (p. 111). In contrast to much of the research done by Indigenous scholars and researchers, however, current research carried out by academics from all health disciplines often continues to portray Aboriginal women as 'participating in risk-taking behaviours' in their efforts to save themselves or as 'disconnected from Indigenous culture' (Jones, 2004; Mill, 1997; Reeves, 2007). This promotes the view that we, as Aboriginal women, are totally devoid or ignorant of the cultural teachings and knowledge that come from our own peoples and may be 'used to' support the development of a positive self-image and a healthy sexuality. A good example of this point can be found within the research findings that were presented at the 2007 "Sex and Sexuality" conference held in Salsberg, Austria. In a presentation entitled, *The impact of Post-Colonial Euro-Christian culture on the sexual identity and practices of Canadian Aboriginal women*, it was argued that "the shift in 'sexual construction' from pre-colonial to present times, combined with negative social determinants, such as poverty, have resulted in…poor sexual health outcomes for many Aboriginal women today" (Reeves, 2007, p. 1). Although I do somewhat agree with the assessment that Aboriginal women today often experience poor sexual health outcomes as a result of these combined conditions, the findings that were presented from this research provided no evidence in support of the researcher's interpretations of Aboriginal women and their 'reported' sexual health practices and behaviours. Statements such as, "it is clear for many [young Aboriginal] women, [that] pleasing their partner is their primary objective" provide little if any insight into the *impacts of post-colonial Euro-Christian culture on the sexual identity and practices of Canadian Aboriginal women*; yet clearly, they can be viewed as disrespectful and as showing a blatant disregard for the knowledge that these women do possess.

During the early stages of engagement with my research, I found that these types of findings and the ways in which they were reported helped me to understand that my own work required a framework that would help to dissipate these damaging views and renew our current understandings of Aboriginal women's sexual health. Utilizing an approach or a framework capable of this shift from 'mainstream' views and positions meant that its perspectives had to be based upon a 'lens' that could appropriately see and interpret, and then help to articulate the points of meaningful discourse on the sexuality and sexual health of Aboriginal women. Not only would such a 'lens' result in the choice of most appropriate methods within an Indigenous research framework, but it would further reveal the need for clearly establishing appropriate research contexts. I later came to recognise that developing and conducting this research in this way meant that I was essentially working towards two separate but inter-related goals. First, I wanted to do a research project that could support and enable a 're-discovery' of the knowledge that Aboriginal women do possess and have available to them through the traditional teachings and knowledge of their ancestors. Second, I would be contributing to the further articulation of an Indigenous research framework for conducting culturally appropriate and respectful health research with Aboriginal women and their communities. The Indigenous research processes that were developed and evolved during this study represent a significant shift from current approaches in sexual health research with Aboriginal women.

Identifying and addressing the many challenges inherent in working with Indigenous peoples from within western intellectual frameworks of research required that I, as the researcher, trust in my own knowledge and experiences as an Indigenous person. This also meant that I needed to trust in the knowledge and lived experiences of my research cohorts, the Aboriginal women and community members who participated in the project, and the women Elders who worked with me during the study and provided expertise through describing and interpreting their own knowledge and understanding of relevant cultural teachings and knowledge. This trust would become important to the efficacy of the research and how such efficacy may impact future health research and health education that Aboriginal women and their communities might access because it is based on the common belief of many Aboriginal peoples that the answers to their health and wellness concerns lie within their own traditional knowledge systems and communities.

Forging this trust was of paramount concern for several specific reasons. First, due to the potentially stigmatizing and intimate nature of the research topic (sexual and cervical health) working with communities, Elders, and Aboriginal women who have experienced cervical cancer illness required that the research be focused initially on the building of relationships rather than on research outcomes or my own learning. Second, the sexual health of Aboriginal women is viewed as culturally developed and determined, and therefore its significance must be derived from within its cultural context. While the implications of current sexual health research have been criticized for their tendency to categorize the reported ill sexual health of Aboriginal women according to the participation or non-participation in health-promoting behaviours, such as cervical cytology screening; Aboriginal female sexuality, when understood from within the cultural contexts of Cree and Métis women, crosses long-established boundaries of personal and social cultural construction. This includes the cultural significance that Cree and Métis peoples attribute to the role and power of women as life-givers. This role is referred to as being gifted from the Creator and is taught as being entrenched within a 'sacredness' that crosses physical, spiritual, and cosmological boundaries. From this perspective, then, all life is viewed as sacred and women are viewed as possessing 'creative powers' and playing an integral role in the life cycles of their peoples and communities. Moreover, this research project and its culturally significant topic ultimately represented an area of health research that has seldom been discussed openly with First Nations and Métis knowledge holders, traditional teachers, and Elders in the formal research arena. For this reason alone, the decision to develop and carry out this study from within an Indigenous research framework, one that specifically reflected adherence to Cree and Métis protocols of relationship and activities, was essential to the success of the project.

Conducting the research from within such a research framework enabled the research and its processes to adhere to the specific cultural protocols of the research participants and the communities involved in the study. An important outcome of these choices was the establishment of an effective process of building a research community of trust (Weber-Pillwax *et al.*, 2008). Working with the guidance and under the direction of the women Elders involved in the project helped me to step back and allow the research process to unfold logically and naturally into this research community of trust. To engage the women Elders in the research, I traveled to their homes and communities to explain the research and the proposed work and to formally invite their commitment to the project. These informal visits were instrumental in gaining the trust and support of the women's communities, other community members, several of the female research participants, and even the women Elders themselves.

Another important issue that arose during this research in relation to working with Aboriginal peoples from within western intellectual frameworks of research was the decision-making around language of usage and communication. One challenge associated with the use of language during this research was the processes that were required to make the results useful to communities. In light of the language that research results tend to use, such as this dissertation and the future publications of its findings, I became acutely aware that much of the language used to describe these findings is not the language of non-researchers and most community members. Although I realized that I needed to use this language and these approaches in order to obtain my education, I also recognized that explicating the concerns and knowledge of Aboriginal women and their communities in forms that are useful to them was and remains key to my ongoing relationships with these women and their communities. This included the recognition that the vocabulary, in specific terms and concepts, that health researchers often use to describe the current concerns and issues important to the health and wellness of Aboriginal women is not found within the first languages of Aboriginal peoples. However, in situating this research within an Indigenous framework, the values and the principles of the Cree and Métis participants had to guide the development of relevant linguistically and appropriate strategies to return the findings to the communities in ways that will be useful and beneficial to them. Setting the appropriate contexts for carrying out this research included grounding the research in the principles and protocols of the participants themselves and thus ensuring that the research will more easily be returned to communities in languages, forms, and concepts that are easily received and understood by community members.

The direct involvement of Aboriginal female Elders, traditional teachers, and/or traditional knowledge holders during this research was also key to its success. If I had chosen to conduct the research in ways that did not call upon this expertise, it would have been more difficult to ensure the validity of the findings. Of special note, any of the interpretations that may have been presented regarding the significance of cultural teachings, norms, and practices for the sexual health and overall health of Aboriginal women would have been severely constrained by the limits of available research and literature in this area and my own personal knowledge. In the end, because I live, work, and have ongoing relationships with many Aboriginal women and Elders in communities across Northern Alberta, and because I am a Cree-Métis woman myself, the people who chose to work with me on this project were all of Cree and Cree-Métis origin. Although I had not intentionally set out for this to be the case, I am grateful in many respects for these outcomes because I have learned and come to better understand about the cultural knowledge and teachings of my own ancestors through this process. In particular, as I worked to analyse the data of the women Elders, I experienced challenges on a very personal level that required my careful consideration. This again underscored the importance of appropriately and openly articulating the personal and social contexts of this research.

The study was conducted in what may be considered three separate, but inter-related phases. The second and central phase of the research was conducted with five Northern Alberta Cree and Cree-Métis women who have experienced cervical cancer. The first and third phases of the research were conducted in collaboration with Cree and Cree-Métis female Elders also from several communities across Northern Alberta. These first and last phases of the research were carried out in order to learn about cultural teachings and knowledge that are significant for the sexual health of Aboriginal women and to gain further insight into how specifically Cree ways of life was manifested in the health and illness experiences of the women who shared their stories.

In analysing the data of the Elders, I understood from the onset that a great deal of what I would learn regarding cultural teachings and knowledge would be contained and embedded within their stories. In order to examine and discuss their stories and teachings in a culturally respectful manner, I had to ensure that my approach was not one of 'putting words in the mouths of Elders'. I did this, in part, by identifying that the interpretations of the stories and cultural teachings of these women Elders were being written in order for me to share how I understood or interpreted the teachings, and did *not* necessarily reflect the knowledge and cultural understandings that were held by the Elders themselves. However, the processes that I went through in arriving at my conclusions and interpretations were demanding emotionally, mentally, and spiritually.

As well, I faced challenges that are inherent in working with two inter-related, but separate sets of information, that of the women and that of the women Elders. Again a great deal of time and personal energy was required in order to analyse and re-analyse two sets of information in ways that would support the development of accurate and sound interpretations of the data. Additionally, the relational nature of Aboriginal cultural teachings and knowledge was realised, however, through analysing these two data sets and finding that the data from the Elders did, in fact, build upon the lived experiences of the women as shared in the stories of their health and wellness.

Recognising the interconnected nature of these data sets reinforced the needs and intentions of this research (from within an Indigenous framework) to acknowledge the relationships that were instrumental in gaining and articulating the insights of the research findings. In particular, acknowledging the sources of these insights – the women, the women Elders, and the communities – included naming the sources of the knowledge or the Elders involved in the research and developing strategies and plans to return the data and its findings to the women and the communities involved.

Cultural teachings and knowledge are multi-layered and necessarily reflect Indigenous ontological and epistemological constructs. The nature of Indigenous cultural teachings and knowledge to reflect the ontological and epistemological considerations of a peoples' worldview is true of any system of knowledge and drew me to the conclusion that Indigenous knowledge(s) is, in fact, its own complete system(s) of knowledge, consistent with an inherent integrity of meanings. This was demonstrated through the findings of this research that showed the cultural teachings and knowledge of Cree and Cree-Métis peoples to be embedded in the stories and lived experiences of these particular Aboriginal women and in their own shared perceptions of their Indigenous female identity.

In talking about constructs and concepts that are ontologically and/or epistemologically bound and unique, the relationships and inter-relationships inherent in the foregoing discussion are necessarily complex. I spent a great deal of time and energy in trying to grasp and articulate many of these relationships and inter-relations that I found implied and/or embedded within the knowledge and cultural teachings of the women Elders. With regards to how I came eventually to understand and interpret the cultural teachings and traditional knowledge of Cree and Cree-Métis peoples, this included relationships and inter-relationships among the several sources of that knowledge – the ancestors, the spiritual realm, and ultimately the Creator – as well as the relational aspects within Indigenous knowledge itself. There were three conclusions that I was drawn to in what I consider to be a very rudimentary understanding of the complexity of Aboriginal cultural teachings and knowledge.

1) I recognised and must acknowledge the skill, intellect, and foresight of the women knowledge holders and traditional teachers who possess sound understandings of these relationships and inter-relationships and then are able to teach this to others through telling stories.
2) It became apparent that, in order to develop even a beginning understanding of these complex ideas and relationships, the need to 'shift' my thinking, and sometimes consciousness, is sometimes required.
3) Finally, the recognition that Cree and Cree-Métis cultural teachings and knowledge, as part of a complete system of knowledge, to have developed concrete avenues for this 'shifting' of one's view speaks clearly to the validity

> of Indigenous knowledge systems as complete knowledge systems that emanate from sources outside of ourselves – such as ancestors, the spiritual realm, and ultimately the Creator.

Indicative of Indigenous paradigms of thought were the relationships and inter-relationships that emerged with regards to the work with women Elders and the work with the women who shared their health and illness experiences. This meant that I was essentially working from within two very different and sometimes polar paradigms of research. One drew upon methods from several disciplines that comprise western paradigms of research and learning and the other encompasses and is entrenched within Indigenous ways of being and coming to know, such as the worldviews of the Cree and Cree-Métis peoples of Northern Alberta. Although many Indigenous researchers may find themselves in a similar position facing similar challenges, what we all likely have in common is that despite working from within these very different and distinct traditions, we respond from within our own traditions or by using what we bring to the particular situation – our own worldviews. Hence, the relational nature of the processes and findings of this research point to the need to work from within the appropriate contexts in order to gain results that can then be articulated and understood from the perspectives that are situated within those traditions and contexts. In this work, I provide a description of the two separate but inter-related processes that occurred in my learning during this research process and this demonstrates the concept of 'relationality' that is inherent within those Indigenous worldviews and Indigenous knowledge systems with which I am familiar.

Self-transformation was another important process of my learning during this project and may be viewed as significant in the development of Northern Alberta Cree and Cree-Métis individuals (Weber-Pillwax, 1999/2003). Implicit to this process, also in a Northern Cree sense, are self-observation and reflection. During a conversation with my peers at the University of Alberta, it was stated that the capacity of the Northern Cree to practice the self-observation and reflection necessary for personal transformation is likely one of the mechanisms that have enabled their very survival as a people. A comment made to me by one of my peers validated this when she stated, “As a Cree person, you are expected to pay attention to yourself”. This discussion, I came to realise was a source of validation for my own learning in relation to this research.

Personal transformation of the women, and in particular, of myself as the researcher provided the basis for many of the insights gained during this project. For example, self-observation and reflection as elements of my own personal transformation during this work are what led me to theorize more deeply about the women’s lived experiences and the ‘re-affirmation’ of their female Cree and Cree-Métis identities. Through our discussions and in shared and solitary reflections upon our lived experiences, the women and I underwent transformations that allowed for the further articulation of these ideas, such as our abilities to draw upon our inherent knowledge as Cree and Cree-Métis peoples. During the conversation with my peers, it was stated that the capacity to undergo personal transformation is a key component in the re-affirmation of our identities as Northern Cree and Cree-Métis peoples. What I was able to identify through this research is that an important part of our inherent knowledge as Cree and Cree-Métis women teaches us to value and appreciate ourselves as Cree and Cree-Métis individuals.

I am able to call this knowledge inherent because analysing the stories of the women who participated in this study and reflecting upon my own experiences as knowledge provided evidence of Cree and Cree-Métis identity formation as flowing also from our genetic makeup and as emanating from sources outside of ourselves. As I reflected upon the women’s experiences and my own experiences, I realised that the attempts of those individuals who played primary roles during our childhoods to eradicate any ‘Aboriginal’ sense of identity, intentionally or unintentionally, had not resulted in the women or me, for the matter, to forsake or lack the recognition of this sense of ourselves. In reading the work of other Indigenous scholars, such as Lawrence (1999) and her work *‘Real’ Indians and others: Mixed-Race urban Native people, the Indian Act, and the rebuilding of Indigenous Nations,* I found further evidence for this theory. For example, Lawrence (1999) talks about a Native sense of identity as flowing from family and family history and how these experiences were subdued and silenced by colonial intrusion, hegemony, and life circumstances. She writes about the experiences of her own mother as the 'other' in trying to survive as a lone-parent Indian woman in an Acadian environment during the sixties and seventies in Eastern Canada:

> *My mother lived in fear of having her children taken away from her. This imposed severe constraints on us, as she did not dare to appeal to social assistance, and always insisted that rent and bills had to be paid first, so that we would not appear to be in crisis, even if that left almost nothing for food. Her hard work paid off, in that she was able to maintain us as a family in the face of tremendous odds. But the price of this struggle for survival has been an absolute ruthlessness on her part about abandoning anything-including any identification with Native people-which might stand in the way of our survival as a family. The social stability which whiteness represents has been something which has been fought for, tooth and nail, in my family (Lawrence, 1999, P v).*

Lawrence (1999) refers to the abandonment of one's Native identity and provides descriptions of Native experience that caused members of earlier generations, such as her mother, to "leave their Native communities behind" (xxvii). As I contemplated on the experiences of my own parents and grandparents, their circumstances and stories held similarities that could also be viewed as 'leaving their Native identities behind'; however, reviewing my own experiences as an Aboriginal woman and hearing the similar stories and memories of the female research participants consistently revealed that we have not left these identities behind nor have we abandoned them. Our identities as Aboriginal Cree and Cree-Métis females has remained fairly intact, I believe, because ancient Cree and Cree-Métis knowledge and teachings are accessible to us as individuals through our own blood connections with our ancestors. Alluded to by several of the participants several times during the course of this study, blood memory as a concept has been referred to in the recent works of several Indigenous scholars, including Fontaine (2001), *Neither here, nor there: A reflection on Aboriginal women and identity.* In this work, Fontaine (2001) talks about her own experiences and the experiences of her study participants with blood memory when she states:

> *Blood or cell memory represents one of these very critical variables in the formation of the participants' identity. Blood memory is similar to having a pass into your history, culture and spirit as an Aboriginal person even if you didn't have that knowledge or access to these elements before. It is an assured connection to those ancestors who have come and gone before you as well as to those who are yet to come. Having experienced some of these same things (ie. recognition of Aboriginal culture prior to having any teachings, etc.) I myself absolutely believe in this realm of possibility (p. 49).*

Blood memory, in this context, is discussed by Fontaine's (2001) research participants as significant to the development of their identities. Exploring Aboriginal women's views and positioning of themselves within contemporary society, Fontaine (2001) refers to the complexities of Aboriginal female identity through her descriptions of participant stories that represent what she calls a "multiplicity of voice, place and identity" (p. 5). She states:

> *...I argued cautiously that a new space was being created because as Sara Mills notes in Discourse 'we will never know what those cultures were really like' (1997: 120). All the information I had for the purpose of this research was the voices of contemporary Aboriginal women who have and operate from within this time and space. While they often spoke of their mothers and grandmothers in a light that illustrated how these particular women were oppressed and sometimes confused in their identity, I can not know that for sure. Indeed, much literature portrays Aboriginal women as powerful, strong willed and assertive and I do not doubt this for a minute. What I don't know is how they conceptualized their identity. As such, all I can determine is that I believe the women who were*

*interviewed for this particular research are creating a new post-colonial space in which to reclaim and reconstruct their identity how they see fit (p. 60).*

Within my own research, the findings may also be thought of as representing the complexities of Aboriginal female identity in which there emerged elements or themes that are similar to what is discussed in the work of Fontaine (2001), Goudreau (2006), Lawrence (1999), and Weber-Pillwax (2003). However, in contrast to the arguments put forward by Indigenous scholars, such as Anderson (2000) and Fontaine (2001), I would argue cautiously (with regards to the discoveries, realisations, and findings with the women in this research) that Aboriginal women are, at least in some senses, not so much 're-creating', 'un-creating', 're-claiming' or 're-constructing' new identities as they are affirming and re-affirming long-existing identities that are within their very beings by way of 'blood memory' and genetic makeup. The aforementioned example of blood memory and the findings of this research suggest that these women, despite egregious and damaging life experiences, inherently possess elements of a 'positive construction' of themselves and that the Elders, by way of and through virtue of the knowledge and teachings from ancestors, have always possessed positive constructions of Aboriginal female identities. What we have not had readily available to us is the ability to articulate these.

Neither the women participants of this study nor I have the language and vocabulary of our ancestors that would enable us to more easily and appropriately articulate what it means to have a positive construction of ourselves as Aboriginal/Indigenous beings and Cree and Cree-Métis women. Neither have the Cree and Cree-Métis Elders, until recently, had the freedom to participate openly in the discussions and sharing of these meanings with younger women. This can be viewed as one result of colonial intrusion and imposition on the languages and cultures of Indigenous peoples across the world. Indigenous and Aboriginal Elders struggle to pass on the teachings and knowledge that contribute to the development of positive female Indigenous and Aboriginal identities. However, many of the women they want to teach do not have the ability to speak their native languages. This is evidenced in my work and in the work of other Indigenous scholars who talk about the significance of retaining Indigenous languages (Battiste & Youngblood Henderson, 2000; Weber-Pillwax, 2003).

The potential significance of these research findings revealed that the impacts of the loss of language and culture for the health and wellness of Aboriginal women are greater than what is currently acknowledged within health research, health education, and service delivery. This also provided further support for the assumption that the teachings and knowledge of our ancestors are inherent within the peoples and come from sources outside of ourselves while demonstrating the relational nature of Indigenous knowledge(s) and coming to know as Indigenous people(s).

For many Indigenous peoples, a yearning to understand our First languages is a common experience. For me, as an Aboriginal student researcher, the reality of this journey took on new and deeper meanings. Both of my deceased grandparents were fluent Cree speakers, however, I had been unable as a child to spend sufficient time with them that would enable me fluency in the language. In carrying out this research, I realised and experienced on many levels the loss of my grandparents as something that wounded the very core of my Indigenous being. This became abundantly clear to me in my feelings of sorrow and deep regret for the lost opportunity to share and learn from these experiences together.

In recognising the sources of the teachings through naming the Elders who participated in this work, the research framework in this study was based in Indigenous tenets or principles – such as the principle that states researchers have the responsibility to identify and honour the origins of the knowledge that is gained or created during a process of knowledge enquiry or research (Atkinson, 2000; Ermine *et al.,* 2004; Martin, 2002; Smith, 1999; Weber-Pillwax, 2003). This principle may be viewed as Aboriginal and/or Indigenous. Similarly, many of the underlying philosophies, theories, and principles may also be viewed in this way. Within the methodology section of this thesis and throughout the work, I talk about these assumptions, theories, and principles as Indigenous and make specific exceptions only in those cases where they are identified as belonging to a specific cultural or linguistic group. A prime example of this is the discussion within this work on the Medicine Wheel.

During our ongoing relationship, Elder Alice Reid has talked about and begun giving me some of the teachings that are contained within the Medicine Wheel. Whether its origins lie with the Algonquin peoples or the Cree and Cree-Métis peoples of the North has never been specifically identified in these conversations. In fact, Alice has always stated that she learnt these teachings from her grandparents who were both Cree and Cree-Métis peoples of Northern Alberta. Their origins, in this sense, has become less important than the teachings that are held within the wheel and their significance for the spiritual, mental, physical, and emotional well being of those who draw upon the power and knowledge that the wheel encompasses. Moreover, a great deal of what the Elders had discussed revealed that many of their teachings possess the same assumptions of teachings held by cultures from across the globe. This was pointed out several times when the Elders referred to their presuppositions with regards to the Creator and his existence. During the one-day session with the Elder women, both Isabel Auger and Alice Reid referred to these teachings and talked about their value for the spiritual wellness of all people – Aboriginal and non-Aboriginal – within any environment.

In relation to the applicability of this research to different populations or cultural and linguistic groups of Aboriginal women, I note the following similarities between my findings and the findings of Goudreau (2006), Fontaine (2001) Lawrence (1999), and Weber-Pillwax (2003) in several areas. Examples include their discussions and descriptions of blood memory, spirituality, and specific teachings from different Elders and traditional teachers who have been involved in their own very different research projects. In some scholarly work, where the focus is on the significance of traditional Indigenous or Aboriginal knowledge for the development of strong Indigenous identities and healthy Indigenous populations, the need to differentiate, explicate and detail the variety of cultural and linguistic origins and sources of ancient Indigenous or Aboriginal knowledge becomes insignificant and unnecessary. In such cases, the specifics of the various cultural teachings are not primary consideration; the fact that these teachings exist within each people's culture and that they have similar impacts on the identities of each people, individually and collectively, is what counts as significant. What one Indigenous people has learned through time and experience is easily transferred or shared with another Indigenous people. That is a principle at the heart of Aboriginal personal and social relationships, intra and inter-people/community.

Health research and health education service and delivery professionals who want to work effectively with diverse Aboriginal populations in Canada need to discover the social contexts that support the formation of healthy Aboriginal identities, and to understand what that means in relation to working with one particular cultural and linguistic community or one Aboriginal people. This understanding leads health policy communities, including health practitioners, politicians and leaders, towards the realization that they require impenetrable connections with Aboriginal communities and community members if they are to develop effective systems of health education, programming, and policy in support of Aboriginal peoples' health. The fact that this country was and is comprised of many distinct Aboriginal peoples, each with varying numbers of their own communities, in no way changes this analysis. In a similar way, I feel that much of what I have learned during this research with a relatively small group of Northern Alberta Cree and Cree-Métis women and women Elders is directly relevant to the larger Canadian context of multiple culturally and linguistically distinct populations of Aboriginal women.

This research and its framework represent one example of a culturally appropriate and respectful research approach in which to engage and learn of the sexual health and illness experiences of Aboriginal women. Through adhering to the protocols of the Aboriginal people and communities, specifically Cree and Cree-Métis involved in the study, I engaged in activities and processes that adhered to Indigenous principles of respect, reciprocity, and relationship building. These principles permitted the creation of a culturally appropriate and safe environment for the research participants, both women and Elders. From this environment or research context, the women could share potentially stigmatizing information connected to the stories of their lived experiences, and the Elder women could engage with one another and the researcher for the purposes of sharing cultural teachings and knowledge. Based in processes that focused on the building of relationships, rather than on my learning as the researcher, engagement with the women and the Elders contributed to the rich and meaningful data that evolved, was articulated, and collected during this research.

As a graduate student, it was very hard at times to meet my obligations to my own family community, the research community I was building, and the university as an institution during this work. Striking a balance between contact with participants and interference in their lives were also challenges during this research. When I realized that significant meaning was inaccessible to me in the Cree data, my inability to speak my own first language was a source of emotional pain and loss throughout the research process. Further, this inability and my own inexperience as a researcher contributed to a lack of clarity around the logistics and practicalities of using translators during the work. In all of this, however, what I learnt is that most of the research challenges could be overcome through taking the time and spending the necessary personal energy to build trusting relationships with research participants and members of my Aboriginal community.

# ABORIGINAL FEMALE SEXUAL HEALTH IN A CONTEXT OF CERVICAL CANCER AND CERVICAL CYTOLOGY SCREENING WITH REFERENCE TO THE CREE AND CREE-MÉTIS OF NORTHERN ALBERTA

## CHAPTER ONE: COMING TO THE QUESTIONS

> *Among the most repugnant aspects of Western research for Native people in the historical context, has been the emphasis of research on negative social issues; described as the application of a pathologizing lens.... briefly, Indigenous people argue that research, which has primarily focused on social disarray and pathos, is evidence of a perspective of 'deficiency' whereby Native people and their lives are pathologized. (Ermine et al., 2004, p. 12)*

Sexual and reproductive health is an area of research that epitomizes the portrayal of Aboriginal peoples[4] with "evidence of a perspective of deficiency" (Ermine *et al.*, 2004, p. 12). Within current health research and literature, Aboriginal women[5] are identified as the one homogenous group experiencing epidemic proportions of cervical cancer, persistently taking part in risk-taking behaviours, and refraining from or participating less in cervical cytology screening. The search for solutions to these concerns inadvertently or directly places the blame on Aboriginal women through the formal presentation of Aboriginal women as less knowledgeable and/or neglectful in relation to their sexual health. This view is demonstrated in the preoccupation and objective of the health care community to decrease cervical cancer incidence and deaths among Aboriginal women through the development of health education and health service delivery that focuses on increasing knowledge of cervical cytology screening or decreasing risk-taking health behaviours.

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[4] Aboriginal peoples, according to the 1982 Constitution of Canada, are those who identify themselves as having Indian, Métis, or Inuit heritage. In this sense, they are viewed as one homogenous group within health research and literature despite national, regional, and cultural diversities.

[5] Aboriginal women in Canada are also referred to as Indigenous women within health research and literature. Within this research, the words "Indigenous women" are used to bring together the concept of sisterhood among First Nation, Métis, and Inuit women and their connection to the land and not as a way to suggest that all these women are part of one larger homogenous group of women.

"Aboriginal female sexual health in a context of cervical cancer and cervical cytology screening with reference to the Cree and Cree-Métis of Northern Alberta" is an innovative research project with Cree and Cree-Métis women from several communities across Northern Alberta, Canada. This research was conducted in three phases with Cree and Cree-Métis women who have experienced cervical cancer, and Cree and Cree-Métis women Elders, teachers, and knowledge holders who are recognized within their communities as having expert knowledge of their culture, traditional norms, and teachings. The project sought 1) to investigate and analyze the significance of cultural traditions, teachings, and knowledge in the sexual health and overall health of Aboriginal women, and 2) to gain new insights into the significance of culturally informed knowledge in the sexual health of Aboriginal women, especially in relation to cervical cancer and cervical cytology screening.

It was the aim of this research to understand the cervical cancer experiences of Aboriginal women from Aboriginal women's perspectives and within Aboriginal lived realities. Embedded in Aboriginal people's cultural teachings and knowledge are the keys to interpreting and understanding the significance of culture for Aboriginal female sexual and overall health and to providing new insights and understandings for the factors that influence and support the sexual health of Aboriginal women. Through the discovery and renewed understandings of Northern Alberta Cree and Cree-Métis women's cervical cancer experiences, this research project sought to reclaim the knowledge of our ancestors in order to gain further insight into one illness related to the sexual health experiences of Aboriginal women and to learn of the traditional teachings and knowledge that Aboriginal culture provides to Aboriginal women, thereby assuring their very survival into contemporary society. The articulation of knowledge that explains and exemplifies the integral relationships that exist between Aboriginal culture and Aboriginal women's sexual health and overall health may contribute to improved sexual health education and service delivery thereby decreasing the subsequent deaths from cervical cancer among Aboriginal women.

In this first chapter I talk about the pathologizing nature of western health research on Aboriginal and Indigenous women and outline variations in the social environment that are used to support the negative orientations of these populations within health research literature and discourse. I conclude this part of my discussion through identifying a significant gap in the sexual health research on Aboriginal women and list the goals and aims of this research that were developed in order to address this issue as it particularly relates to cervical cancer. In Chapter two, I review cervical cancer research and literature and summarize several of the factors that are believed to be culturally specific or situated for Aboriginal and Indigenous women in relation to the prevalence of cervical cancer and their reported non-participation in screening activities.

### *Cervical Cancer as an Aboriginal Woman's Disease*

Acutely aware that they are already marginalized within Canadian society, the common theme that always seemed to emerge when I spoke with Aboriginal women about this disease was the fear that western medicine is only too eager to label cervical cancer an Aboriginal woman's disease. Within health research, several issues may be identified that legitimize these fears and concerns of Aboriginal women regarding cervical cancer and cytology screening. First, health research continues to persist in its movement towards solutions and improvements for Aboriginal women's health within a 'deficit model' approach. Exemplified through the awareness of many Aboriginal women of the negative risk factors associated with cervical cancer, such as multiple sex partners and childbearing at an early age, these approaches are also recognized as a source of frustration for Aboriginal researchers attempting to address gaps in health research from a holistic or Aboriginal perspective (Chaudhry, 1998; Wilson, 2002). For example, the *Aboriginal Women and Girl's Health Roundtable* (National Aboriginal Health Organization, 2005b) found that a primary concern of health professionals and researchers working in the area of Aboriginal women's health was reported as the forced adaptation or "fit" of applications into mainstream models or "deficit models" in order to access funding or financial support (p. 11). An examination of the research and reports that have been produced to design and support cancer education and screening programming for all women, consistently reveal that their underlying theories or focus is on the increased awareness of screening and participation in screening activities (Aboriginal Cancer Control Strategy Committee, 1999; Alliance of Cervical Cancer Research, 2004; Chaudhry, 1998; Health Services Utilization and Research Commission, 1997; Pan American Health Organization, 2000; Population Reference Bureau, 2004; Wilson, 2002; World Health Organization, 2002). Aboriginal women, identified and representative of the one homogenous group of women in Canada with the most immediate needs in relation to cervical cancer, then become the targets of this type of research as they are reported to present with the least knowledge of screening and participation in screening activities (Alliance for Cervical Cancer Research, 2004; Chaudhry, 1998; Clarke *et al.,* 1998; Grunfeld, 1997; Health Canada, 2002; Lanier & Kelly, 1999; Lonky, 2002; Martin *et al.,* 1995; Wilson, 2002; Young *et al.,* 2000). Further, it can be suggested that the newly available Human Papillomavirus (HPV) vaccine[6], and its related programming within health services and delivery, will only continue to perpetuate and reinforce these views of Aboriginal women in relation to health research on screening practices.

As well, while most health research recognizes the significance of culture as an important consideration for successful health education and service delivery to Aboriginal peoples, most of the research that claims to address the problems of Aboriginal women and their health from a cultural perspective focuses on constructs that are now commonly used and defined within western contexts of health. For example, literature and research that report findings within an Aboriginal cultural context or within the lived realities of Aboriginal people use terms such as holistic or refer to the Medicine

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[6] The newly developed HPV vaccine, Gardasil, is discussed in further detail within chapter two. The development and delivery of this vaccine to young females across the world is considered to have potential significant future impacts on the incidents and development of cervical cancer illness.

Wheel and the spiritual, mental, emotional, and physical dimensions of the person (Aboriginal Health, 1992; Browne & Fiske, 2001; Browne & Smye, 2002; Clark *et al.*, 1998; Hislop *et al.*, 1996; Reynolds-Turton, 1997; Royal Commission on Aboriginal Peoples, 1996b; Solomon & Gottlieb, 1999). However, these same scholars and researchers usually fail to provide accurate definitions for these concepts or describe the context from an Aboriginal perspective. Described as a "lack of recognition/validation of Aboriginal definitions", this failure of health research to corroborate the meanings of such fundamental constructs as Aboriginal health and healing with Aboriginal philosophies and ideologies makes less viable or attainable solutions that will ensure "accessible, holistic, language and culturally appropriate health services" (National Aboriginal Health Organization, 2005b, p. 13). Bartlett (2005) demonstrates this point when talking about the meanings of Aboriginal health and healing through her statement, "[M]inimal academic exploration has been done to document…the meaning of these terms with Aboriginal populations. Most health survey questions, even in Aboriginal-driven surveys, have not been validated for congruency with Aboriginal culture" (p. 22). This is of vital importance to Aboriginal women as Aboriginal interpretations and understandings of traditional teachings and practices considered essential to or integral to female sexual health remain largely absent within current health research and literature (Anderson, 2000; Bartlett; 2005; Bennett, 2005; Dion Stout & Kipling, 1999; Newhouse, 1998).

Further, health research acknowledges that addressing the health concerns and realities of Aboriginal women and communities may best be affected through changes in policy and practice that guide health education and service delivery. However, the majority of current research appears to have produced limited changes to actual policy or practice (Browne *et al.*, 2000; National Aboriginal Health Organization, 2005b; Pan American Health Organization, 2000; Royal Commission on Aboriginal Peoples, 1996a; World Health Organization, 2004). This is evidenced by the fact that several national and international health organizations have hosted roundtables and produced large working papers in relation to Aboriginal/Indigenous women and sexual health, yet few programs have been developed that see this information as critical to the development of health education and service delivery (Alliance for Cervical Cancer Prevention, 2004; Browne & Fiske, 2001; Dion Stout & Kipling, 1999; National Aboriginal Health Organization, 2005b; Pan American Health Organization, 2000). For example, *Lifestyle Series Teaching Packages for Health Professionals in Alberta's Regional Health Authorities* (Alberta Cancer Board, 2001) developed a teaching package for 'Cervical Screening and Prevention' which states, "A population-based organized cervical screening program" is currently being implemented within Alberta aimed at all women in Alberta (p. 16). Hence, despite the overt recognition in health research and literature for the need to develop and deliver programs that are "age and gender specific" and "responsive to local values and culture", the hope of such programming becoming a reality is at the least, a long way off (Dion Stout & Kipling, 1999, p. 13). Moreover, regardless of their special circumstances in relation to cervical cancer and cervical cytology screening, Aboriginal women will continue to be treated as part of the larger group of all Albertan women and will not be targeted as a specific group with specific needs.

Trapped within deficit model approaches, health research with Aboriginal women, continues to define Aboriginal cultural perspectives within a western context, and thereby fails to impact health policy and practice. At the same time, such research approaches reinforce the fears and apprehensions of Aboriginal women in relation to further research of their cervical health and sexual health concerns. By maintaining a focus on increased awareness of screening activities and increased screening participation for Aboriginal women, cervical cancer research will likely continue to develop education and programming that indirectly suggests that Aboriginal women are less knowledgeable and more neglectful of their sexual health than other women, generally. To add further complexity to the situation, the creation of health research, education, and service delivery models that include Aboriginal perspectives, will not likely be of much benefit if these perspectives are defined and described within western contexts of health and wellness. As well, the common response of many Aboriginal peoples in relation to health research is that they already suffer from "research fatigue" (Ermine *et al.,* 2004, p. 12). In light of the fact that current health research has produced little change in health policy and practice, the challenge and concern for all cervical cancer research with Aboriginal women is 1) clarity about the way such research is framed so as to avoid the possibility of naming this an Aboriginal woman's disease and 2) grounding such research within an Aboriginal lifeworld so as to develop solutions that are culturally appropriate and acceptable to Aboriginal women and their communities.

### *Eurocentric Dominance in Aboriginal Women's Health Research*

> *Eurocentrism is the imaginative and institutional context that informs contemporary scholarship, opinion, and law. As a theory, it postulates the superiority of Europeans over non-Europeans. It is built on a set of assumptions and beliefs that educated and usually unprejudiced Europeans and North Americans habitually accepted as true, as supported by 'the facts,' or as 'reality'. (Battiste & Youngblood Henderson, 2000, p. 21)*

Historically, it can be argued that Eurocentric[7] perspectives and values dominate the research on Aboriginal peoples (Battiste & Youngblood Henderson, 2000; Cajete, 2000; Ermine *et al.*, 2004). Characterized by "an emphasis on coherent wholes", two central methods of interrogation have been imposed on the Indigenous peoples of the world (Battiste & Youngblood Henderson, 2000, p. 31). These methods, ethnographic traditions of research and biomedical research, have enabled governments, including their institutions and research, to absolve themselves of any responsibility for the poor state of Indigenous communities (Battiste & Youngblood Henderson, 2000).

Ethnography, seeking to "describe human societies as manifest through their cultures in scientific terms", aims to identify those patterns or 'shared meanings' that set a particular cultural group apart (Battiste & Youngblood Henderson, 2000, p. 30). One distinct advantage of this approach is that comparisons between cultural groups then become possible. Although many scholars from many disciplines have criticized the inherent limitations of ethnographic approaches to research with Indigenous peoples, a constant within current research, and one that may be considered a mainstay of the ethnographic tradition is the classic Eurocentric notion of homogenization (Battiste & Youngblood Henderson, 2000; Blaut, 1993; Coombe, 1991; Said, 1992). Viewing Indigenous peoples or Aboriginal women as homogenous groups, easily identified through often imposed shared meanings and similar characteristics has led to research that focuses on a limited set of issues, specifically those dealing with health and healing, violence and abuse, and the criminal justice system (Dion Stout, 1996a/1996b/1996c/2005; Dion Stout & Kipling, 1998, p. 5/2001; National Aboriginal Health Organization, 2005b; Royal Commission on Aboriginal Peoples, 1996a; The Aboriginal Healing Foundation, 2004). Dion Stout, a respected Aboriginal nurse, scholar, and health educator talks about the limited sets of issues that have been addressed in health research regarding Aboriginal women and describes this tendency as a "singular, negative orientation" (Dion Stout & Kipling, 1998, p. 7). Dion Stout and Kipling (1998) further explain, "despite the heterogeneous nature of the problems.... With surprisingly few exceptions, work dealing with Aboriginal women has tended to be highly problem-focused, and it has pathologized these women's agency and realities. This in turn has allowed little room for an understanding of the real complexities at work, and has provided little insight into the strategies that work" (p. 7).

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[7] Eurocentrism encompasses those ideologies, knowledge systems, and practices associated with European histories and peoples and which were directly & purposefully imposed upon Indigenous peoples of the world.

Biomedical approaches similarly tend to seek out patterns, which may then be applied to study the "nature, causes, prevention and eradication of disease" (Southwest Foundation for Biomedical Research, 2006, p. 1). Enabling the discovery and explanation of patterns of increased disease incidences among particular groups or communities; biomedical approaches to health research with Aboriginal peoples have focused on health status and behavioural health risks (Elias, 2003, p. i; National Aboriginal Health Organization, 2005b). For Aboriginal women, in relation to cervical cancer research, biomedical approaches have almost squarely placed the emphasis on behavioural health risks through identifying, categorizing, and scrutinizing the 'risk-taking' or health-promoting behaviours of this community (Band, *et al.,* 1992/1995; Canadian Cancer Society, 2004; Franco *et al.,* 2001; Healey *et al.,* 2001; Health Canada, 2002; Health

Services Utilization and Research Commission, 1997; Hislop, *et al.*, 1996; Lonky, 2002; MD Consult, 2005; National Cancer Institute of Canada; 2001; Pan American Health Organization, 2000; Reath & Usherwood, 1998; Strickland *et al.*, 1996; Wilson, 2002). In this instance, the focus on the behavioural health risks of Aboriginal women has begun to stagnate and all research now works towards the increased participation of Aboriginal women in screening activities. Albeit increased participation in screening activities may be one key to decreased rates of cervical cancer among Aboriginal women, the majority of research fails to address culture, or any other potential factor as significant to the improved cervical health of Aboriginal women. Progress in the efforts to reduce the rates of cervical cancer among Aboriginal women continues to be focused on understanding and measuring rates of participation in screening activities. Under the guise of health promotion, Indigenous women are fitted into the description of a 'singular, negative orientation' and are subjected to the judgments and values of ideologically Eurocentric research which ultimately negates any responsibility of governments and institutions for the poor state of health experienced by these women (Dion Stout & Kipling, 1998). Moreover, in relation to the incidence of cervical cancer, blame can then be assigned to individuals according to their decisions to participate or not participate in what has been deemed health-promoting behaviour.

This overwhelming tendency of current research to view Aboriginal peoples, Aboriginal women, and their health in pathologizing terms has contributed to an environment that is fraught with disadvantages for health research. These disadvantages or limitations of current health research on Aboriginal women include the tendency to focus on a limited set of issues and the tendency to view Aboriginal women through a singular, negative orientation (Dion Stout *et al.*, 2001; Dion Stout & Kipling, 1998). As outlined in the Status of Women Canada publication by Dion Stout and Kipling (1998), *Aboriginal Women in Canada: Strategic Research Directions for Policy Development,* the results of these tendencies have led to a "shocking disregard for the views and interests of Aboriginal women" and a "severe lack of information concerning their day-to-day lives and the impact of their activities on their families and communities" (p. 6). Further, the general tendency of research and literature to focus or stay within the narrow boundaries of health behaviours, despite the complex nature of the health problems and concerns of Aboriginal women, will likely continue to reap solutions that are restrictive, problem-focused, and judgmentally values-laden. Dion Stout & Kipling (1998) acknowledge that Eurocentric perspectives and values tend to dominate the health research on Aboriginal women and suggest that, "[T]his situation is not likely to change in a truly fundamental fashion until the country's policy makers and political leaders have before them detailed and well-supported data pertaining to the lives of Aboriginal women" (p. 6).

### *Aboriginal Women, Racism & Gender Discrimination*

Racism against the Aboriginal peoples of Canada continues to pervade modern society. Despite claims that the social consciousness and multicultural climates of today no longer tolerate this damaging and dehumanizing behaviour towards different ethnic groups, it seems acceptable to chastise and degrade Aboriginal women publicly. For example, a recent publication of the Alberta magazine, *Insider Report*[8] (2006), stated that Colleen Klein, a Métis woman and wife of then-Alberta Premier Ralph Klein, will be "just another Indian" once this Premier leaves public office. I am not suggesting that all Canadians share such sentiments; however, current situations such as the legal battle between energy giant Epcor and the Papachase Cree people of Alberta[9] for repatriation of their grave site in the Edmonton river valley or the roadblocks set up by Six Nations near Caledonia[10], Ontario to stop housing developments on ancestral lands at least brings into question the underlying attitudes of governments and their officials. Additionally, and in relation to the poor health that is experienced by Aboriginal women, marginalization in the form of racism has been reported as a significant factor and barrier to access of health services for Aboriginal peoples in general (Benoit *et al.*, 2003; Bent, 2004; Browne & Fiske, 2001; Browne *et al.*, 2000; Brunen, 2000; Elias, 2003; Ellerby *et al.*, 2000). Nursing scholars and researchers, Meleis & Im (1999), mirror these assertions in their statement regarding the healthcare experiences of clients from minority cultures: "[I]t is the extent to which they are stereotyped, rendered voiceless, silenced, not taken seriously, peripheralized, homogenized, ignored, dehumanized and ordered around. The inequities that people experience in the societies where they are living tend to marginalize them and to deprive them of quality care" (p. 96).

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[8] In April, 2006, *The Edmonton Journal* ran an article about a story in the *Insider Report* (Insiderreport.net) quoting the above statement. It was never revealed in either article where the quote originated.

[9] "From Castles to Forts" (P. Coutu, 2004) provides a historical account of Cree and Métis people of the Fort Edmonton region and refers to the repatriation of the gravesite and ancestral lands currently occupied by Epcor Energy.

[10] See "Caledonia problem didn't arise overnight" at *First Perspective: National Aboriginal News* written by FP/Drum Staff. Available online: http://www.firstperspective.ca/fp_template.php?path=20060525caledonia

Gender discrimination, as it is experienced by Aboriginal women is often associated with and exacerbated by the high rates of physical violence and sexual abuse that these women endure (Amnesty International, 2004; Brownridge, 2003; Cohen & Maclean, 2004; Dion Stout, 1996b/1996c, Dumont-Smith, 1995; McGillivray & Comaskey, 1999; The Aboriginal Healing Foundation, 2004; Zellerer, 1996/1999/2004). Bennett (2005) refers to the multiple forms of physical and sexual violence perpetrated against Aboriginal women and highlights several facts that she considers to be "a result of the systemic realities of living within Canada" as an Aboriginal female (p. 146). These include the following: higher rates of spousal abuse; higher rates of children who witness violence; higher rates of victimization; experiencing more severe forms of violence; and the approximately 500 Aboriginal women gone missing in communities across Canada over the past 20 years (Bennett, 2005, p. 146).

Gender discrimination and racism for Aboriginal women in Canada, whether they are the products of or a result of colonial intrusion and forced marginalization, have undoubtedly been detrimental to the health of this population and contributed to the creation of an environment in which Aboriginal women experience epic proportions of teen suicide, teen pregnancy, poverty, sexually transmitted infections and HIV, increased levels of alcohol and drug abuse, sexual abuse, sexual exploitation, loss of land and culture, and the struggle to maintain a cultural identity, to name a few (Centre for Aboriginal Health Research and Northern Health Research Unit, 1998; Dion Stout, 1996a; Dion Stout & Kipling, 1999; Human Resources Development Canada & Statistics Canada, 1997; National Aboriginal Consultation Project, 2000; The Aboriginal Healing Foundation, 2004; Turtle Island Native Network, 2003). Although the implications of gender discrimination and racism upon the health and well being of Aboriginal women are multifaceted and complex, the negative effects on this population is likely related to a cycle of oppression that Anderson (2000) describes as "the construction of a negative identity…[that] can rule a Native woman's experience" (p. 111). For the many contemporary Native women who find themselves "locked into this imagery" (Anderson, 2000, p. 112) the lived realities of this cycle of oppression may be reflected in the following statements by Dion Stout & Kipling (1998):

> *…the combined effects of racism and sexism served to degrade and marginalize Aboriginal women within their own communities, even as they continued to exercise considerable power over particular facets of family and community life…. It is precisely this legacy which Aboriginal women continue to live with to this day. Not only are they often expected to be able to raise their children and secure a livelihood, with little or no help from their spouse, but in many cases they are also forced to endure physical and sexual victimization at the hands of this same partner, over a period spanning years or even decades (p. 25).*

### *Variations in the Social Environment*

For health research that intends to uncover misconceptions regarding Aboriginal women's sexual health and to discover cultural knowledge and teachings that affect their sexual and cervical health, it is imperative that the research envelops a sound understanding of the environment in which Aboriginal women live. This includes an awareness of the impoverished living conditions and socio-economic inequalities for many of the participants and how this might affect decisions to participate in the research and its processes, an acknowledgement of the possible influences of the Residential School Legacy on the health and well being of the participants, and thoughtful consideration of the persistent political context or atmosphere that pervades the lives of Aboriginal peoples.

In relation to health research, poverty is generally accepted to be the main determinant of health. According to the World Health Organization (2004) and the Pan American Health Organization (2000), poverty may be viewed as a constant in the lives and communities of Aboriginal peoples (Royal Commission on Aboriginal Peoples, 1996a; Weber-Pillwax, 2001; Young, 1994). The significance of poverty as a constant for the Aboriginal peoples often goes unrecognized by researchers as their work is primarily carried out within the context and parameters of western research (Battiste & Youngblood Henderson, 2000; Masuzumi & Quirk, 1995; Smith, 1999; Weber-Pillwax, 2001; Wilson, 2001). This context does not factor in the different aspects of the social environment within which a research query is embedded; it does not even require that these aspects be fully identified by a researcher. The role of poverty therefore has not been factored into mainstream research on Aboriginal women and cervical cancer. Neither, for that matter, have many other aspects of the social realities of Aboriginal women. Underlying this segmented approach to research is a difference in how knowledge itself is viewed by Western science and Indigenous science.

Western research tends to view knowledge and the acquisition of knowledge as an inherent right of the researcher. From these perspectives, knowledge is viewed in relation to ownership and control and western science holds largely to the assumption that "knowledge is an individual entity" and may therefore be sought by, be gained by, and be owned by the individual (Wilson, 2001, p. 176).

Indigenous scholars Cardinal (2001), Meyer (2001), and Wilson (2001) address Indigenous perspectives of knowledge through talking about the relational nature of knowledge. Within an Indigenous context, these scholars purport that knowledge is only really knowable when seen through its relationships with the rest of the universe. Wilson (2001) talks about relational knowledge as the kind of *thing* that is shared with all of creation and Meyer (1998) acknowledges that, "we, by ourselves, cannot bring about the kinds of knowing that endure" (p. 128). Viewing knowledge as relational, rather than "absolute" or as fitting into a subset or "process of classification", therefore establishes the responsibility of the research and the researcher (Battiste & Youngblood Henderson, 2000, p. 36). These responsibilities include that any knowledge or outcomes of the research itself must credit and acknowledge where the knowledge came from and name the person or persons who were instrumental in the knowledge being gained.

When knowledge, then, within a western system, is seen to lie outside of a relational context, the researcher is ultimately justified to claim knowledge as his/her own and this position thus alleviates any responsibility for payment or reciprocity. From an Aboriginal perspective, the giving of gifts to receive knowledge is equated with notions of balance and harmony. For example, particular practices that accompany ceremony and rite often reflect the giving and receiving of a gift. The gift giver may be Mother Earth, who is "not considered a metaphor", but a living and breathing entity from whom Aboriginal persons in their being cannot be separated (Little Bear, 2000, p. 78). Acceptable research processes to engage with Aboriginal women in a dialogue about personal and cultural understandings would encompass practices of gift giving to ensure balance and harmony between the giver of knowledge and the receiver of knowledge.

The Residential School Legacy, which may also be considered a variation in the social environment of Aboriginal women, reflects further cause for concern as its negative impacts on the lives and well being of Aboriginal peoples are only recently being acknowledged within society. In 1990, Phil Fontaine, a former Chief of the Assembly of Manitoba Chiefs informed the Roman Catholic Church representatives and the press of the abuse that he and many other people experienced over the years that they attended residential schooling. "I think what happened to me is what happened to a lot of people. It wasn't just sexual abuse, it was physical and psychological abuse. It was a violation" (Miller, 1996). As Aboriginal leaders have begun to break the silence, the Residential School Legacy has become a topic of much debate and tension. Aimed at the assimilation of Aboriginal peoples into the dominant society, the residential school system may be considered a construct of the Federal government's colonial policies that involved the cooperation of several Church organizations representing a huge source and cause of intergenerational abuse, specifically sexual abuse, among many First Nations, Inuit, and Métis peoples of Canada (Auger, 2005). The 2002-2003 First Nations Regional

Longitudinal Health Survey (National Aboriginal Health Organization, 2005c) reported that although approximately 80% of First Nations adults did not attend a residential school, 75% felt that their grandparents' attendance at a residential school negatively affected the parenting their parents received and the subsequent parenting that they personally received.

Finally, although it can be argued that politics and government policies affect the lives of all Canadians, no other group possesses a more complex or historically subordinate position within Canada than Aboriginal peoples. And nowhere is this evidenced more strongly than in the areas of health research and health service delivery. Much research and literature clearly advocates that health care education and services to Aboriginal people be delivered by Aboriginal peoples (Dion Stout & Kipling, 1999; National Aboriginal Health Organization, 2005a; Reading & Nowgesic, 2002; Royal Commission on Aboriginal Peoples, 1996b; Waldrum *et al.*, 1995). Some of the rationale that supports this recommendation addresses issues related to Aboriginal self-worth, racial discrimination against Aboriginal peoples, a lack of understanding of the issues and cultural norms of Aboriginal peoples accessing education and/or services, a lack of understanding of Aboriginal languages, a lack of understanding of the intertwining of religious and cultural beliefs that are held by Aboriginal peoples and communities, the inappropriateness of the service provider to teach or deliver the type of service that is being accessed, the lack of readiness of service providers to offer opportunity and involvement of family and community in education and service delivery, and the lack of readiness and understanding of service providers to provide education and services that include and allow for the expression of Aboriginal spirituality (Dion Stout, 2005; Dion Stout & Kipling, 1999; LaRocque, 1993; Royal Commission on Aboriginal Peoples, 1996b; Scott, 1997; The Aboriginal Nurse, 2002a/2002b). The list goes on and involves many important issues that Aboriginal peoples have identified and continue to identify as affecting their health and decisions to access health care and health education services. For Aboriginal women who may be experiencing an illness related to their sexual health (an area of health care that is broadly recognized as sensitive, private, values-laden and culturally situated), the list is ever longer and more complex. It has been said that meeting the health needs of Aboriginal peoples through the provision or availability of Aboriginal health care providers seems unrealistic or unattainable; so, filling this need has prompted governments, researchers, and health care service providers to focus on the training of mainstream non-Aboriginal health care providers in specific ways, namely through the development of cultural competence and culturally sensitive or appropriate or specific care (Brown & Fiske, 2001; Cameron & King, 2004; Kavanagh *et al.*, 1999; Leininger, 1995; National Aboriginal Health Organization, 2005a; Nunez, 2000; Paasche-Orlow, 2004; Royal Commission on Aboriginal Peoples, 1996a; Society of Obstetricians and Gynaecologists of Canada, 2001; Thomas, 2002). It seems logical, then that in order to develop services that are culturally competent and/or sensitive, health care systems will be expected to first define the "kind" of care and expertise that is needed and that will form a part of that "cultural competence" or sensitivity training. It becomes obvious surely that these issues are complex and that health research has much work to do in order to inform health care policy and practice in the area of culturally competent or sensitive care. Further, this knowledge would then need to be translated into frontline health care education for the enhancement of service delivery and the increased relevant knowledge of service providers working with Aboriginal communities.

### *Variance in Aboriginal Women's Sexual Health*

Current health research and literature shows variances in the sexual health of Aboriginal women in comparison to mainstream Canadians. Replicating the previously noted tendency of health research to focus on a limited set of issues while viewing Aboriginal women through a singular negative orientation, the majority of research in relation to Aboriginal female sexual health deals with cervical cancer[11], HIV/AIDS, sexually transmitted infections or STI, sexual violence, abuse, and exploitation

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[11] Recent advances in diagnoses and treatment – such as a sexual health history inclusive of sexual activity and the presence of STI's – suggest that cervical cancer may be viewed as a sexual health concern and may be better understood outside the limited context of a gynecological concern.

(Aboriginal Nurses Association, 1996; Brownridge, 2003; Bucharski, 2005; Bucharski *et al.*, 1999; Calzavara *et al.*, 1998; Centre for Aboriginal Health Research and Northern Health Research Unit, 1998; Clarke *et al.*, 1998; Cohen & Maclean, 2004; Craib *et al.*, 2003; Hankins *et al.*, 1997; Human Resources Development Canada & Statistics Canada, 1997; Johnston *et al.*, 2005; Jolly, 1993; Jones, 2004; Martin *et al.*,1995; Mill, 1996; Neron, 2000; Steenbeek, 2004; Tanner Spence, 1996; Young *et al.*, 1997/2000). As well, there is a significant body of research related to the reproductive health of Aboriginal women, most of which falls under the themes of motherhood, birthing, infants, and obstetrical and/or gynaecological concerns (Bennett, 2005; Benoit *et al.*, 2001; Bent *et al.*, 2004; Chalmers & Wen, 2004; Loppie, 2004; Martens, 1997/2002). Moreover, and similar to the research on Aboriginal women and sexual health, much of this literature reports that problems and concerns tend to be pronounced when compared to non-Aboriginal women and important issues, such as enforced sterilization, FAS/FAE, and teen pregnancy are often given prominence (Bennett, 2005; Chamberlain *et al.*, 2001; Fletcher, 1993; Kaufert & O'Neil, 1988a/1988b/1990; Tait, 2000; Weber *et al.*, 2003; Wilson, 2002). Although it should be noted that a small amount of research attempts to move beyond these parameters, the mere handful of available articles of this nature suggest the need for further exploration and research in this area and reveal a significant gap in research on Aboriginal women's sexual health (Aboriginal Nurses Association, 1996; Anderson, 2000; Asetoyer *et al.*, 2003; BC Aboriginal HIV/AIDS Task Force, 1999; Braveheart-Jordan & DeBruyn, 2005; Dion Stout, 2005; Dion Stout & Kipling, 1998; Loppie, 2004; Maracle, 1993; Marsden & Newmann, 2001; Ontario Federation of Indian Friendship Centres, 2002b; Pauktuutit Inuit Women's Association; 2002; Razack, 1994/1998/2000; Ship, 2000; Ship *et al.*, 1999; Ship & Norton, 1998/2001).

Several reasons for this significant gap may be suggested. First, it may simply be the case that health researchers, including several Indigenous organizations and scholars are disinterested, hesitant, or too uncomfortable to discuss Aboriginal women's sexuality and sexual health. Other possible explanations for this apparent hesitation may be related to the focus of current information on a negative set of issues, the lack of available information, and the challenges associated with collecting this type of information. For instance, in the article "HIV Study among Pregnant Aboriginal Women Raises Concerns", Thomas (2002) submits that there is an alarming trend towards certain types of research with Aboriginal communities and cites one study that uses unlinked HIV seroprevalence among pregnant Aboriginal women in British Columbia (Bennett, 2005, p. 184). This article, which examines the implications of such research to suggest HIV prevalence among pregnant Aboriginal women in British Columbia without sufficient evidence, raises concerns similar to what Hoffman-Goetz *et al.,* (2005) reveal in their look at mass media, HIV/AIDS, and the portrayal of Aboriginal women. In this case, even the media coverage within Aboriginal newspaper articles are shown to portray discriminatory negative images of Aboriginal women associating them with HIV/AIDS and HIV/AIDS research. Mass media such as this neglects to mention the risks for heterosexual men while placing emphasis on the lack of knowledge held by Aboriginal women regarding HIV/AIDS (Bennett, 2005) and research such as "Pregnant Aboriginals More Likely to be HIV-Positive" (Jones, 2004) and "HIV Risk Behaviours Become Survival Techniques for Aboriginal Women" (Mill, 1997) suggest that current health research and literature in the area of Aboriginal women and sexual health continue to be trapped within deficit model methodologies while reinforcing the negative and pathologizing portrayal of this population.

Second, in light of available statistics related to the sexual health and activity of Aboriginal peoples, little effort is made to place this information within relevant and important cultural contexts. For example, current literature acknowledges a direct correlation between the age at which sexual activity begins and the increased risks to sexual health and overall health (Alberta Health and Wellness, 2004; Centre for Aboriginal Health Research and Northern Health Research Unit, 1998; McKay, 2000; Pan American Health Organization, 2000; Steenbeek, 2004). In their article on youth and sexual health, Feldmann & Middleman (2002) state, "the younger the age at first sexual intercourse, the more lifetime partners teenagers accrued," and the less likely youth are "to use contraception, putting this group at much greater risk for pregnancy, STI and HIV" (p. 490). Although this may indicate the significance of variances in the sexual health of all youth, there is no accompanying information that attempts to place this information within historical, social, or cultural contexts or that even questions the culturally specific attitudes and beliefs that might affect early sexual activity or childbearing at an early age.

Third, the 2002-2003 First Nations Regional Longitudinal Health Survey (National Aboriginal Health Organization, 2005c) reveals that the most pressing sexual health concerns of First Nations communities include pregnancy at an early age or unplanned pregnancy, STI and HIV/AIDS, a limited awareness of the risks for disease or unwanted pregnancy, and a lack of available culturally appropriate or sensitive programming. Despite the information that culturally specific and culturally appropriate health programming has been shown to significantly affect the access and utility of these services by Aboriginal peoples, the tendency of governments and agencies to import a 'pan-Aboriginal' approach in the development and delivery of sexual health education and programming for these populations tends to be the norm (Aboriginal Nurses Association of Canada & Planned Parenthood Federation of Canada, 2002; Alberta Health and Wellness, 2004; Auger, 2005; Dion Stout & Kipling, 1999; Letendre, 2005; National Aboriginal Consultation Project, 2000; Pan American Health Organization, 2000; The Aboriginal Healing Foundation, 2003; The Aboriginal Nurse, 2002a/2002b). This situation has been addressed repeatedly in the recommendations of all research and major literary works regarding Indigenous peoples and sexual health and warrants the attention of governments and policy-makers.

Fourth, in the 2002-2003 First Nations Regional Longitudinal Health Survey (National Aboriginal Health Organization, 2005c) two relatively small chapters were dedicated to Aboriginal peoples and their sexual health; both chapters emphasized the need for culturally appropriate and sensitive research in this area (Auger, 2005 & Letendre, 2005). The extremely limited availability of this type of research and literature may suggest that even institutions (e.g. NAHO), dedicated to the development of culturally sensitive and culturally appropriate research that works towards the improved health of Aboriginal peoples are hesitant to discuss sexual health and sexual health issues in any great detail. Further, the considerable lack of research and literature in this area may be due to just such hesitations and the apparent discomfort of researchers to broach these topics.

Finally, within a cultural context, the discussion of Aboriginal sexuality and female sexual health may be considered a complex issue that has been and remains compounded by the arrival of European Christianity and its teachings. For example, society's view of sexuality is reported to have a huge impact on sexual health and sexual activity (Alberta Health and Wellness, 2004; Feldmann & Middleman, 2002; McKay, 2000; National Aboriginal Consultation Project, 2000; Pan American Health Organization, 2000; Steenbeek, 2004; The Aboriginal Nurse, 2002a/2002b). The National Aboriginal Consultation Project (2000) states that "our impressions of what is desirable and undesirable in terms of sex…is very local, very specific to a moment in time, a group of people, and a place on the globe" (p. 7). This may have particular impact on Aboriginal peoples as European and religious ideas that go against traditional knowledge and teachings help to create an environment where "two conflicting views of sexuality exist" (Newhouse, 1998, p. 3). Newhouse (1998) suggests that non-Aboriginal traditional views of human sexuality often possess explicit characteristics that associate sex and sexuality with sin and uncontrollable passions and these are viewed as a primary motivation for behaviour. Aboriginal traditional views see sex as a gift to humans from the Creator and the act of sex as something that is meant to be pleasurable. This dichotomy of views, representing a significant source of conflict for many Aboriginal people, envisions the need for research to return to traditional Aboriginal teachings and values in order to renew current understandings of Aboriginal women in relation to sexuality and sexual health.

A significant gap in the health research and literature on Aboriginal women, their sexuality, and sexual health has been shown to exist. Although important work has been done by Aboriginal scholars and organizations such as Anderson (2000), the Aboriginal Nurses Association of Canada and Planned Parenthood Federation of Canada (2002), and the Aboriginal Women's Health and Healing Research Group (Bennett, 2005), the sexual health of Aboriginal women is usually examined in relation to overall female health or in terms of the cultural significance of women as life givers and mothers. From a holistic perspective, this would seem appropriate as the sexual health of the female does not exist in isolation from the rest of the person. However, of significance is that little research has been done that describes the cultural knowledge or traditional teachings that Aboriginal women utilize to maintain and improve their sexual health and overall health. Due to the lack of available research and literature in this area, this research represents a groundbreaking opportunity to learn about Aboriginal women's sexual health from cultural perspectives that have largely been undisclosed, ignored, and/or inaccessible in the past. Moreover, this contributes significantly to the minimal amount of current reliable and valid information for developing a comprehensive knowledge base of the factors that affect, comprise, and support the sexual health of Aboriginal women.

As this information has previously been relatively inaccessible to researchers, the importance of trusting and ongoing relationships between Aboriginal women and culturally respectful Aboriginal researchers becomes clear. Further, discussion and discovery of cultural knowledge, teachings, and norms that might affect the sexual health of Aboriginal women may best be achieved through the guidance of those community members deemed to have well developed and accurate understandings of their culture – community Elders, traditional teachers, and knowledge keepers. The involvement of Elders, traditional teachers, and knowledge keepers in the pulling together and interpretation of this research and its processes were paramount as the research objective was to gather relevant data while simultaneously gaining reliable interpretations of the cultural significance of the data. Therefore, a vital and fundamental component of this research was the initial and ongoing close consultation with these knowledgeable Aboriginal community members.

### *Cervical Cancer as Subject or Context*

Within a culturally specific framework, appropriate sex education programming means specific to gender, to age, to community, and to traditional values and practices while being cognizant of the healing required from the effects of colonialism and the marginalization of Aboriginal peoples (The Aboriginal Nurse, 2002a). Further, sex education that does not encompass traditional teachings of sexuality, gender roles and responsibilities, motherhood as a meaningful community role, and the inclusion of men in these practices and processes is deemed insufficient (Dion Stout & Kipling, 1999). As well, the direct involvement of Aboriginal communities in the development of sex education programs is paramount to their success while culturally trained educators are viewed as essential if the programs are to successfully alleviate any feelings of alienation, isolation, self-worth, and discrimination (Aboriginal Nurses Association of Canada & Planned Parenthood Federation of Canada, 2002; BC Aboriginal HIV/AIDS Task Force, 1999; National Aboriginal Consultation Project, 2000).

These statements comprise the findings of roundtables and reports that identified concerns and developed plans of action for addressing the immediate sexual health disparities and sexual health education needs of Aboriginal peoples across Canada. Within the current pathologizing environment and in light of the 'disparaging' health status of Aboriginal peoples, it becomes difficult to assume that the current approaches and directions of health research will markedly affect cervical cancer incidence and deaths among Aboriginal women any time in the near future. Unless a change occurs in the availability and nature of culturally specific and appropriate sexual health education and cervical cytology screening for Aboriginal women and their communities, few health care service providers will be taught the significance of cervical cancer for Aboriginal women. Even fewer will be armed with the skills to address these issues in culturally appropriate ways or in which to approach Aboriginal women on issues of sexual health. Moreover, health research and literature recognizes that the development of culturally appropriate programming and education is required to improve the rates of cervical cancer while the preoccupation or focus of health research to decrease 'risky' health behaviours and increase 'good' health behaviours has limited the ability of researchers and health educators to seek new understandings of culturally specific knowledge that supports and maintains the sexual health and overall health of Aboriginal women. Therefore, health research with Aboriginal women in relation to cervical cancer and cervical cytology screening must be grounded in an Aboriginal culturally specific and sensitive framework that acknowledges the holistic approach considered fundamental to addressing the sexual health of Aboriginal women while embracing the involvement of community members as key to any success in identifying Aboriginal women's sexual health concerns and improving their sexual health.

Further, past interests and experiences including the initial development of a research project to focus on cervical cancer and cytology screening led me to discover that the pathologizing nature in which Aboriginal women are viewed in relation to their sexual health and overall health establishes the limited and misinformed understandings of health research and literature on the subjects of Aboriginal female sexuality and sexual health. In order to develop effective and successful cervical cancer and cervical screening programming for Aboriginal women, health research must first discover those cultural norms and values that are seen as fundamental to improving and maintaining the sexual health and overall health of Aboriginal women. In summary then, the discovery of those cultural norms, teachings, and practices that support the sexual health and overall health of Aboriginal women may be further and better understood by the health-care community as these are manifest in the cervical cancer and cervical cytology screening experiences of Cree and Cree-Métis women of Northern Alberta. For these reasons, this research sought 1) to gain new insights into the culturally informed knowledge that influences and supports the sexual health and overall health of Northern Alberta Cree and Cree-Métis women and 2) to investigate and analyze the significance of cultural norms, traditions, and teachings to the sexual health and overall health of Northern Alberta Cree and Cree-Métis women in a context of cervical cancer and cervical cytology screening.

### *Research Questions*

This study was composed of three inter-related phases. The first and third phases of the study were carried out in partnership with Northern Alberta Cree and Cree-Métis women Elders, traditional teachers or knowledge holders who are recognized within their communities as having expert knowledge of their culture, traditions, and teachings. While I did have a set of guiding questions for interviews and consultation, they were never used formally with the Elders and knowledge holders. The following research questions were largely addressed through the research process, which included the women's stories, the ongoing visits with the Elders, and a one-day gathering of the Elders.

1) What cultural knowledge – traditions, norms, and teachings – are significant for the sexual health and overall health of Cree and Cree-Métis women? What are their implicit/explicit meanings for the sexual health of Cree and Cree-Métis women?
2) What cultural norms and values must be considered as significant and important in the development and delivery of sexual health programming and education for Cree and Cree-Métis women?
3) What information is deemed significant to the particular concerns and issues of these Cree and Cree-Métis women and their cervical health? What must be considered if the women are to use the information in ways that will affect their sexual health or choices regarding their sexual health?
4) What are viewed as the appropriate contexts in which to provide sexual health and cervical cancer education and information to Cree and Cree-Métis women?
5) What cultural knowledge or traditional teachings do Cree and Cree-Métis women utilize to maintain and improve their sexual health and overall health? How are knowledge and teachings manifested in the cervical cancer experiences of these women?
6) How do Cree and Cree-Métis Elders, teachers, and traditional knowledge holders interpret the stories of the Cree and Cree-Métis women with respect to cultural knowledge and teachings? What language is used to name and describe the experiences of these women?

Although I had initially anticipated that question 6 would be addressed by the Elders at a gathering in the third phase of the project, I had learned by then that this analysis of the women's experiences with cervical cancer and cervical cytology screening was no longer appropriate to the work and the relationships that had been established with the Elders. In short, I could see that the research process as it had unfolded would not appropriately incorporate this type of analysis.

The second phase of the study was composed of single interviews with five Cree and Cree-Métis women from across Northern Alberta who had experienced cervical cancer. Three questions were used to guide the research interviews with these participants.

1) How do Cree and Cree-Métis women describe their health and illness?
2) How do Cree and Cree-Métis women perceive their diagnosis of cancer?
3) How do Cree and Cree-Métis women integrate their illness into their worldview?

This study explored the role of cultural norms, teachings, and traditions as integral to the sexual health and overall health of Northern Alberta Cree and Cree-Métis women in a context of cervical cancer and cervical cytology screening. A major outcome of this study was to provide healthcare service providers, researchers, program developers, policy makers, and in particular, Northern Alberta Cree and Cree-Métis communities with a description of the cervical cancer experiences of Cree and Cree-Métis women. Additionally, insights are drawn into the culturally specific influences that enhance and support the sexual health and overall health of Cree and Cree-Métis women. Through the natural progression of the research and its processes, extraordinary opportunities were created for the researcher to come together with Cree and Cree-Métis Elders, traditional teachers, and knowledge holders from across Northern Alberta regarding the influences and impacts of culture on the sexual health and overall health of Cree and Cree-Métis women. In order to meet these goals, specific objectives for the research emerged.

1) To examine the cervical cancer experiences of Northern Alberta Cree and Cree-Métis women from within a contemporary cultural context
2) To understand and describe the factors that determine and impact Northern Alberta Cree and Cree-Métis women's sexual health experiences in relation to cervical cancer

3) To examine and study the cervical cancer experiences of Northern Alberta Cree and Cree-Métis women in order to enhance and renew our understanding of the role and significance of culture for the sexual health and overall health of Aboriginal women
4) To seek new understandings from community Elders and traditional teachers regarding cultural knowledge and teachings pertaining to Aboriginal women's sexual health
5) To discover the cultural meanings embedded in Aboriginal women's sexual health experiences

### *Chapter Summary*

Essential to understanding the significance of cultural norms and traditions in supporting and enhancing the sexual health of Aboriginal women, the development of a research foundation built on trusting relationships is paramount. In working with Northern Alberta Cree and Cree-Métis women on a subject that is as sensitive and potentially stigmatizing as cervical cancer and cervical cytology screening, the aim of the research framework was to develop a safe and appropriate research environment (shared environment and responsibilities) where it would be possible to articulate the appropriate patterns and meanings of the findings in relation to health research with Aboriginal women. Further, the development of new knowledge based on the lived realities of Northern Alberta Cree and Cree-Métis peoples might enable the Nursing discipline to develop, implement, and evaluate sexual health education and programming that Aboriginal women would actively seek out and access. Finally, health research that has the potential to renew current understandings and reveal misconceptions about Aboriginal women and their sexual health can ultimately transform and affect health policy, contributing meaningfully and substantially to change in both forms of services and systems of delivery within Aboriginal communities.

This chapter identified the devastating legacy of colonialism and its affects upon the health of Aboriginal women. In addition, a description of the social environment of

Aboriginal women was provided. The relevant research and scholarly literature in relation to the sexual health and the overall health of Aboriginal women was reviewed and a significant gap in research and literature was noted. Further, the current and often pathologizing discourse of health research on Aboriginal women was discussed in connection with the need for culturally specific research frameworks that would enable renewed, more accurate, and informed views of Aboriginal women and their sexual health. Through the rediscovery and renewed understandings of cultural knowledge and teachings that affect, comprise, and support Aboriginal women's sexual health, the development of solutions that are culturally specific and appropriate for the improved health of Aboriginal communities become possible and attainable. Close consultation with Aboriginal women, Elders, and their communities was identified as essential for the development of culturally specific and appropriate health research that intends to support the redevelopment of sexual health education and programming for communities. While the contents of this chapter are dense, the complexity of Aboriginal women's health and Aboriginal women's health research necessitates an in-depth and comprehensive inclusion of the aforementioned material.

# CHAPTER TWO: CERVICAL CANCER RESEARCH & LITERATURE REVIEW

This chapter reviews current literature and research of Aboriginal women in relation to cervical cancer and cervical cytology screening. Important factors that affect cervical cancer and cervical cytology screening among Aboriginal women are identified. Further, international research with Indigenous women in relation to cervical cancer and cervical cytology screening is overviewed and current trends and directions of cervical cancer research are discussed. In conclusion, nursing research directly applicable to this project is summarized.

## *The Role of Information in Relation to Aboriginal Women & Cancer Illness*

Prior to presenting an overview of cervical cancer research and literature, it is important to note that the available information can be seen as problematic in nature. In fact, there are several factors that should be considered before an accurate picture of the significance of cervical cancer among Aboriginal women can be drawn. With regards to the specific populations of Aboriginal women from the province of Alberta, there are few available statistics that identify the prevalence of cervical cancer and/or the numbers of Aboriginal women, First Nations or Métis, who participate in screening. The 'reported' prevalence and participation in screening, at least within this province, can only be extrapolated from other provinces that are thought to have comparable or similar population characteristics in relation to the Aboriginal peoples of Alberta. In addition, the majority of available statistics regarding Aboriginal peoples are based on First Nations data and the available statistics that are inclusive of Métis information are fairly dated, such as the 1991 Aboriginal Peoples Survey (Statistics Canada, 1991). Due, in part, to the ways in which the relevant statistics are gathered and to the ways in which the statistics are presented, the following factors need to be considered in order to draw fairly reliable conclusions.

First, as previously stated, the search for statistics regarding Aboriginal women and cervical cancer incidence or screening participation produced minimal results outside the data collected on First Nations. Second, during this research the 2006 Canada Census data had been collected; however, most of the information that had any direct bearing on this study, as yet, had not been made available. Although some statistics had been made available that may be viewed as relevant to what I report within this section of the document, such as the numbers of Albertans who self-identify as Métis or First Nations, much debate had recently surfaced regarding the accuracy or representation of these results. For example, it was widely reported that some Albertans had begun to improperly or unknowingly falsely self-identify as Métis due to recently acquired hunting and fishing rights. For these reasons and because reliable reports on these statistics had not yet surfaced, I have largely omitted these statistics in this research.

As well and in relation to the Aboriginal women of Alberta, I stated that minimal or no statistics that report cervical cancer prevalence or screening participation were available at the time of this research; therefore, statistics that provide detailed information for specific cultural or linguistic groups of Aboriginal women are even less available to the public or simply nonexistent. This is especially true in relation to statistics and population characteristics that deal with subjects of an intimate or potentially stigmatizing nature, such as the age at the onset of sexual activity and numbers of partners.

Further, it should be noted how the statistics on cancer incidence and prevalence with regards to Aboriginal peoples are determined. During a personal communication with the Alberta Cancer Board, I learned what is summarized here[12]. The statistics on Aboriginal peoples in relation to cancer are forced to rely on First Nations data that is extrapolated from the fees for service that are paid out through non-insured health benefits. Non-insured health benefits, for First Nations peoples, is a federally funded program that pays out fees for health services that are accessed by these individuals across Canada. The National Cancer Institute of Canada then cross-references this information with cancer care related services and fees information to determine what and how many cancer related services have been provided to First Nations peoples across provinces and territories. This information is then used to report an estimate of cancer related incidences and prevalence among the Aboriginal peoples of Canada. Through this process then, the reported 1% of cervical cancers among all cancers experienced by Aboriginal peoples from across Alberta can only be stated as an estimation of actual incidences that have been detected (Alberta Cancer Registry, 2007).

It should be noted that the Alberta Cancer Board[13] is currently in the process of planning and conducting a needs assessment of Aboriginal populations and cancer burden across this province. Again, much of the information will draw primarily on First Nations statistics and until this information becomes available, cervical cancer incidence and prevalence among the Aboriginal women of Alberta will largely be forced to rely on its extrapolation from other Canadian provinces that are reported to have similar population characteristics, such as Saskatchewan and Manitoba.

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[12] Personal Communication — The Alberta Cancer Board. June 13, 2008. Edmonton, AB.

[13] This project is presently in the planning stages and the actual methods of data collection or use of the data are yet to be determined.

### *Overview of Cervical Cancer Research & Literature*

Worldwide, cervical cancer "is the third most common cancer" and the "second most common cancer and leading cause of death from cancer in women in developing countries" (Lonky, 2002, p. 1). In Canada, "1400 women …will receive a diagnosis of invasive cancer and approximately 410 women will die from the disease in the year 2002" (Health Canada, 2002a, p. ix). Further, it is estimated that "371 000 new cases of invasive cervical cancer are diagnosed worldwide each year" which represents approximately "10% of all cancers in women" (Franco *et al.*, 2001, p. 1017). Indigenous women are especially affected by cervical cancer and estimated to have rates that are as much as 3-to-12 times higher than the national averages of non-Indigenous women depending on the particular Indigenous group (Band *et al.*, 1992/1995; Clarke *et al.*, 1998; Franco *et al.*, 2001; Healey *et al.*, 2001; Health Canada, 1999/2002a; Health Canada, Health Canada-1/-2; Hislop *et al.*, 1996; Lanier *et al*, 1999; Lonky, 2002; Orians *et al.*, 2004; Reath & Usherwood, 1998).

Health research estimates that the rates for cervical cancer among Aboriginal women are 3-10 times the national average, continue to increase while survival rates remain low, and are 2.5 times more likely to end in death (Health Canada, 1998/2001/2002a/2004; Kjaer & Nielsen, 1996; Lanier *et al.*, 1999; Lanier & Kelly, 1999; National Cancer Institute of Canada, 2001; Young *et al.*, 2000). For instance, Franco *et al.*, (2001) state that within the Inuit population of Canada, cervical cancer accounts for approximately 15% of all cancers and that the Aboriginal population of Saskatchewan have an incidence of cervical cancer 6 times greater than the national average. Health Canada Statistics also show a 100% increase in the cervical cancer rates of Aboriginal women within the provinces of British Columbia, Manitoba, and Saskatchewan between

1967 and 1986 (Aboriginal Cancer Control Strategy Planning Committee, 1999; British Columbia Vital Statistics Agency (BCVSA) for Medical Services Branch, Health Canada, 1999; Saskatchewan Women's Secretariat, 1999). In addition, the greatest increase in mortality rates for Aboriginal women (increased by an estimated 21% from 1981-1993) is attributed to neoplasm or the category which includes cervical cancer deaths (Health and Welfare Canada, 1996) The significance of these figures speak for themselves, however explanations for these dramatic differences between Aboriginal women and the rest of Canadian women tend to be attributed to the following three sets of conditions: a prevalence of the particular risk factors associated with cervical cancer; the stage at which diagnosis of cervical cancer tends to occur; and, the health behaviours or lifestyle choices of Aboriginal women.

The National Cancer Institute (Canadian Cancer Society, 2004) identifies the following risk factors for women regarding the development of cervical cancer as follows: age (women over the age of 35); sex at an early age (some indications are before the age of 19); childbearing at an early age; multiple sex partners (recent literature indicates this includes the sexual activity of the partner as well); sexual abuse; the use of oral contraceptives; the incidence of HPV (or the Human Papillomavirus – a sexually transmitted infection of which there are more than 100 types); non-participation in cervical cytology screening; and smoking (Band *et al.,* 1992/1995; Coughlin *et al.,* 1999; Franco *et al.,* 2001; Healey, 2000; Healey *et al.,* 2001; Health Canada, 2002a; Hislop *et al.,*1996; Lockwood-Rayermann, 2004; Martin *et al.,* 1995; Orians *et al.,* 2004; Population Reference Bureau, 2004; Reath & Usherwood, 1998; Salmon Kaur, 1999; Tiffen & Mahon, 2006; World Health Organization, 2002). Some literature indicates that the presence of two or more risk factors is strongly correlated with the incidence of cervical cancer (Health Canada, 2004; MD Consult, 2005). Substantial support for each of these risk factors among Aboriginal women is found within the literature on Aboriginal peoples (Canadian Cancer Society, 2004; Health Canada, 1998/2002a; Dion Stout & Kipling, 1999; Pauktuutit Inuit Women's Association, 1999; Population Reference Bureau, 2004; Rosenberg & Martel, 1998; Royal Commission on Aboriginal

Peoples, 1996a; Saskatchewan Women's Secretariat, 1999; World Health Organization, 2002).

**Age:** Age as a contributing factor toward the incidence of cervical cancer among Aboriginal women is an important consideration for two reasons. First, statistics on Aboriginal peoples reveal that the second largest portion of this population falls between the ages of 35 and 44 years (Statistics Canada, 1991/1996/2002b/2003). Second, projection in growth rates for Aboriginal peoples suggest that age will continue to play a role in the incidence of cervical cancer among Aboriginal women. For example, the number of Aboriginal people aged 35 to 54, in 1996, is expected to show a 41% increase by the year 2006 and a 62% increase by the year 2016 (Statistics Canada, 1991/1996/2003). Data from the Statistics Canada – 2006 Census indicate that the number of Aboriginal peoples between the ages of 25-to-34 years increased 17.3% since 2001 (Statistics Canada, 2001/2006). Again, these statistics may be in dispute due to the issues discussed in the previous section.

**Sexual activity and childbearing:** The early onset of sexual activity and childbearing at an early age may be suggested by the statistics for Aboriginal women regarding birth rates and fertility rates. Birth rates for Aboriginal women are conservatively estimated to be 2 ½ times the total population (Royal Commission on Aboriginal Peoples, 1996a; Statistics Canada, 1996/2002a/2002b). This figure may be augmented, in part, due to the average age of the Aboriginal person as 25.5 – 27 years or about 10 years younger than the average age of the general population, which is reported to be 35.4 years (Statistics Canada, 1996/2002a/2002b). In addition, the fertility rate for Aboriginal women is estimated at 70% higher than the fertility rate of the total population (Health Canada, First Nations & Inuit Health Branch, 2002; Royal Commission on Aboriginal Peoples, 1996b; Statistics Canada, 1995/2005). Canadian Aboriginal women have 491 children under the age of 5 for every 1000 women of the total population (Statistics Canada, 1996/2003). 29.4 % of Aboriginal women are estimated to have 4 or more children compared to 18.3 % of the rest of Canadian women with 4 or more children (McKechnie, 1997; Statistics Canada, 2003). These statistics have been reported as decreasing with the total Aboriginal fertility rate falling from 4 times in comparison to the rest of the total Canadian population in the 1960's to 1.5 times in 2001 (Statistics Canada, 2003). Concerns regarding the significance of the early onset of sexual activity among Aboriginal women are expressed within the Aboriginal Roundtable on Sexual and Reproductive Health (Dion Stout & Kipling, 1999) that questions the accuracy of current health research to reflect the numbers of pregnancies for adolescents between the ages of 13-15.

**Multiple sex partners:** The identification of 'multiple sex partners' as a risk factor for the incidence of cervical cancer and its prevalence among Aboriginal women epitomizes the negative stereotypes that are associated with this topic and calls attention to the need for culturally appropriate investigation and literature in this area (Dion Stout & Kipling, 1999). Currently, few statistics directly measure this factor and indications of its occurrence are suggested in the literature on Aboriginal youth and adults regarding trends in sexual activity (Auger, 2005; Letendre, 2005; National Aboriginal Health Organization, 2005c; Steenbeek, 2004). As well, the 2002-2003 First Nations Regional Longitudinal Health Survey (National Aboriginal Health Organization, 2005c) asked First Nations youths and adults questions regarding numbers of sexual partners, however use of this data was yet to be determined at the time of this research.

**Sexual abuse:** The 1997 First Nations Regional Longitudinal Health Surveys (First Nations Information Governance Committee, 2004) reported that as much as 59% of First Nations men within Ontario experienced sexual abuse. Staggering percentages, such as this are intended to reflect sexual abuse as a current social problem within Aboriginal communities; however, what is not represented in this number is the proportion of Aboriginal peoples affected by past sexual abuse or sexual abuse of a parent, grandparent, or partner (Indian and Northern Native Affairs Canada, 1997). Since 1991, several Federal documents have been published which estimate that as many as 34% of First Nations have experienced sexual abuse related to the residential school system (The Aboriginal Healing Foundation, 2003). Although it is beyond the scope of this literature review to discuss the implications of sexual abuse among Aboriginal women, it is important to realize their existence in order to consider the potential impact of sexual abuse as a risk factor for cervical cancer. For example, in his discussion on the effects of the residential school system for Indigenous peoples, Terry Tafoya (2005) told a story of one community he had visited in which there were reports that not a single male from this community had escaped sexual abuse while attending residential schooling. "Imagine", he said, the impact on the health of an entire community and its future generations if all of the men have suffered these egregious experiences (National Aboriginal Health Organization, 2005c).

**Socio-economic status:** Two statistics are considered to be the most reliable in reflecting socio-economic status. They are levels of income and levels of education (Canadian Population Health Initiative, Canadian Institute for Health Information, 2004; Health Canada, 2005; World Health Organization, 2004). In 1991, approximately 42 % of First Nations in Canada lived on social assistance and government transfer payments (Health Canada, 1996; Royal Commission on Aboriginal Peoples, 1996a). In that same year, unemployment rates for First Nations over the age of 15 years was 27.1 %, or more than double the reported 10.3 % for the rest of Canadians. As well, it is estimated that 27.9 % of the Aboriginal population has less than a grade 9 education (Health Canada, 1996/2002b; Statistics Canada, 1996). The 2001 Canada Census data information also reports that 48% of the total population of Aboriginal peoples 15 years of age and older have less than a high school education (Statistics Canada, 2002b).

The Aboriginal Roundtable on Sexual and Reproductive Health (Dion Stout & Kipling, 1999) and the Royal Commission on Aboriginal Peoples (1996a) are two Federal documents produced in partnership with Aboriginal peoples that emphatically state the need for researchers to create safe and appropriate research environments. Recognizing the potential negative impact of these risk factors as prevalent within the Aboriginal population in relation to cervical cancer research is paramount to the development of culturally appropriate and sensitive research frameworks. Further, learning of the contexts in which Aboriginal culture supports the cervical, sexual, and overall health of Aboriginal women requires that researchers have knowledge of the realities of the environments in which Aboriginal women must navigate in relation to sexual health and overall health.

A review of the literature identifies a second important aspect in determining the frequency and distribution of cervical cancer as the stage at which diagnosis tends to occur (Band *et al.,* 1992/1995; Foxall *et al.*, 2001; Hislop *et al.,* 1996; Martin *et al.*, 1995; Orians *et al.,* 2004; Roos *et al.*, 1999). Cervical cancer usually develops slowly and is believed to be the result of changes in the cells, or abnormal cell growth, on the surface of the cervix that eventually spread deeper into the cervix or to surrounding tissues or organs (National Cancer Institute, 2005; Tiffen & Mahon, 2006). Precancerous changes or dysplasia are thought to occur in stages that are measured in relation to changes in the cells on the surface of the cervix (Squamous Intraepithelial lesions or SIL is the Bethesda system and reports details on the quality of the Pap results) and changes in relation to the level of precancerous lesions (cervical intraepithelial neoplasia or cancer precursors graded by CIN I-III) that are present in the cells of the cervix (Farkash, 2005; MD Consult, 2005; Tiffen & Mahon, 2006). The incidence of cervical cancer is said to occur when malignant tumor cells within the cervix or surrounding tissue or organs indicate the presence of precancerous lesions at a level of CIN III, or the most advanced level of cervical intraepithelial lesions (Canadian Cancer Society, 2004; Solomon & Gottlieb, 1999; Tiffen & Mahon, 2006).

Upon the diagnosis of cervical cancer, classification of the extent of the disease is measured in 4 stages according to the *International Classification of Carcinoma of the Uterine Cervix Index* (Bobak *et al.,* 1989; Brunner & Suddarth, 1998; Farkash, 2005). Commonly utilized by physicians, this tool estimates the clinical stage of cervical cancer beginning at stage 1 which involves only the epithelial layer of the cervix and ending at stage 4 where involvement of the bladder is suspected (Brunner & Suddarth, 1998). A diagnosis at stage 4 indicates the need for 'radical' treatment with the increased likelihood of death from the disease by 50 % (Bobak *et al.,* 1989).

Band *et al.*, (1992/1995) estimate that Aboriginal women are 2 ½ times more likely to die following a diagnosis of cervical cancer than the rest of the Canadian women. The stage at which diagnosis tends to occur is considered to be an important contributor to the high death rate of Aboriginal women from cervical cancer as cervical cytology screening designed to detect early changes in cervical cells is reported to be under-utilized by a large portion of the Aboriginal population (Bottorff *et al.*, 2005; Chaudhry, 1998; Clarke *et al.*, 1998; Franco *et al.*, 2001; Healey, 2000; Healey *et al.*, 2001; Health Services Utilization and Research Commission, 1997; Lanier *et al.*, 1999; Lanier & Kelly, 1999; Martin *et al.*, 1995). This under-utilization of cervical cytology screening may be viewed as characteristic of the female Aboriginal population or as a lifestyle factor of Aboriginal women.

It should be further noted that the complexity of this disease with regards to its diagnosis, progression, and treatment may have had a huge impact on the abilities of health education and service delivery to effectively teach the significance of this illness to women of all ages, ethnic categories, and cultures. Suffice it to say that it has taken me several years of study to grasp a rudimentary understanding of the nature of this illness; therefore, it is incumbent upon health researchers and educators to develop strategies that enable comprehensive teaching and learning of the risks and effects of sexual and reproductive diseases in all women.

### *Aboriginal Women & Lifestyle*

The third condition recognized in the literature as influencing the frequency and distribution of cervical cancer is lifestyle (Alliance for Cervical Cancer Prevention, 2004; Calam *et al.*, 1992/1999; Foulks, 1998; Grunfeld, 1997; Healey *et al.*, 2001; Lytwyn & Sellors, 1997). As a population, Aboriginal women exhibit two specific characteristics or health behaviours believed to influence their incidence of cervical cancer. They are the resistance to participate in activities that lead to the early detection of cervical cancer, such as cervical cytology screening, and higher rates of smoking (Band *et al.*, 1992/1995; Coughlin *et al.*, 1999; Franco *et al.*, 2001; Hislop *et al.*, 1996; Lanier *et al.*, 1999; Lanier

& Kelly, 1999; Lauver & Rubin, 1991; Lonky, 2002; Strickland *et al.*, 1996; Wilson, 2002).

Cervical cytology screening or the Papinacolaou (Pap) test is widely accepted as the most effective screening tool and is reported as "[able to] detect abnormal cervical cells 10 to 15 years before cancer develops" (Health Services Utilization and Research Commission, 1997, p. 1). Evidence of the under-utilization of this screening tool for Aboriginal women is found in multiple studies conducted across Canada. For example, the Saskatchewan Health Services Utilization and Research Commission (1997) conducted 6 studies including the analyses of physician billing data, focus groups, and key informant interviews. The results of these studies show that the greatest portion of the Saskatchewan population unscreened in 1994 were Aboriginal women over the age of 40 years or 91 % in comparison to 42 % for any other specific age group or geographic category.

Similarly, Hislop *et al.*, (1996) have done extensive research in British Columbia on Aboriginal Pap screening rates and found that in comparison to the rest of the population, Aboriginal women of every age category participate up to 22 % less in screening activities. Published studies specific to the Aboriginal population of Alberta in relation to cervical screening participation are unavailable so far, however the Native population of Alberta is seen to be very similar in demographics and health status to that of Saskatchewan and British Columbia (Alvi, 1999; Rosenberg & Martel, 1998; Statistics Canada, 1991; Tonita & Alvi, 2004). In addition, Alberta has the largest Métis population of Canada and it is reasonable to assume that equivalent risks for cervical cancer also exist within this province (Elgersma, 2001; McKechnie, 1997; Roberts, 2005).

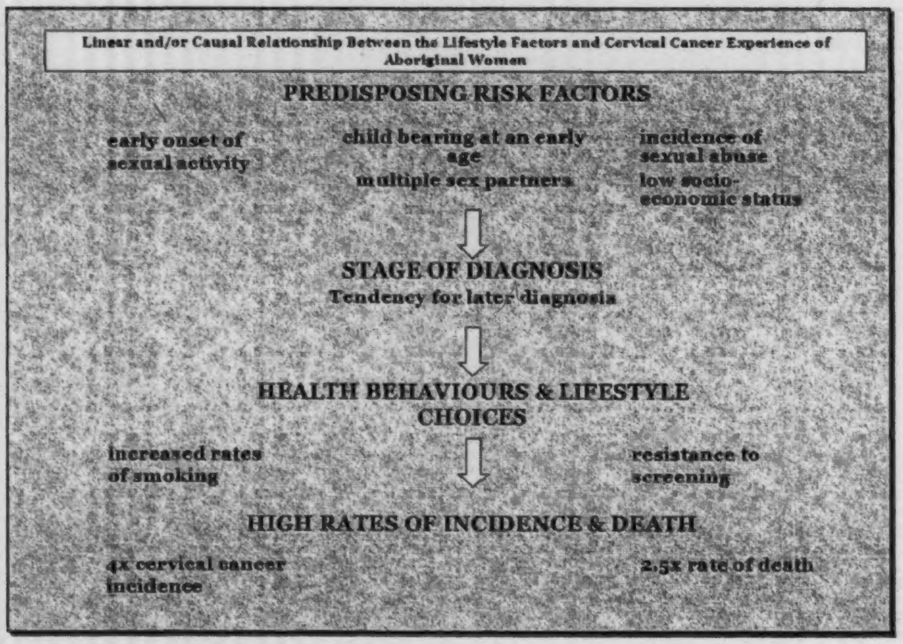
The other lifestyle factor or health behaviour of Aboriginal women that is seen to have a negative impact on cervical cancer rates is smoking (Aboriginal Cancer Control Strategy Planning Committee, 1999; Band *et al.*, 1992; Hislop *et al.*, 1996; Roos *et al.*, 1999). Reading (1999) states that smoking or the non-traditional use of tobacco "poses a significant health risk to contemporary First Nations, Inuit, and Métis people" (p. 5). Aboriginal tobacco consumption is viewed as a very complex health issue and is compounded by the fact that its 'traditional use' is entrenched within most aspects of

Aboriginal culture. National information sessions on the non-traditional use of tobacco for First Nations and Inuit peoples reported that as much as 60 % of the female Aboriginal population are smokers (Reading, 1999). This high rate of smoking has remained constant and perhaps even increased since the 1991/1997 Aboriginal Peoples Survey(s) that report 51 % of all Aboriginal peoples as smokers (First Nations Information Governance Committee, 2004; Statistics Canada 1991). The implications for this behaviour as characteristic of the Aboriginal population reinforce the consideration within the literature that cervical cancer is a significant health concern for Aboriginal women.

A review of the literature to identify the conditions associated with the incidence of cervical cancer indicates that Aboriginal women present with all of the known risks in a high proportion of their population. A preoccupation of current health research in relation to Aboriginal women and cervical cancer is a search for the reasons as to why Aboriginal women experience all of these risk factors to such a large degree; however, few studies are done within research frameworks designed to study cultural aspects specific to Aboriginal health (Bottorff *et al.*, 2005; Chaudhry, 1998; Giroux *et al.*, 2000; Lanier *et al.*, 1999; Lanier & Kelly, 1999; NWT Breast Cancer Working Group, 1997; Salmon Kaur, 1999; Solomon & Gottlieb, 1999; Steven *et al.*, 2004). In fact, culture is often viewed as an indication or precursor to cervical cancer incidence and decreased screening participation, rather than a worldview or set of attitudes and beliefs that affect lifestyle behaviours and choices. For example, Johnston *et al.*, (2005) in their study "Community-Based Cultural Predictors of Pap Screening in Nova Scotia" utilized 'cultural indicators' such as community income, language, and ethnicity and determined that women of Black and Aboriginal heritage are among the less informed and the less likely to have recently participated in screening.

Identification of the risk factors associated with cervical cancer is one area of knowledge that is well defined within the literature. What is gained from an integration of the existing literature on risk factors and lifestyle behaviours is support for the recognition that Aboriginal women are less likely to participate in activities that lead to the early detection of cervical cancer. What is termed a 'resistance' to participate in activities, such as cervical cytology screening, and higher than the mainstream mortality rates for cervical cancer indicate that barriers to participation exist for Aboriginal women. Figure 1 provides an overview of the causal relationship that is suggested to exist between the lifestyle of Aboriginal women and cervical cancer experience.

Figure 1: Lifestyle Factors & Aboriginal Cervical Cancer Experience


Linear and/or Causal Relationship Between the Lifestyle Factors and Cervical Cancer Experience of Aboriginal Women
PREDISPOSING RISK FACTORS
early onset of sexual activity
child bearing at an early age
multiple sex partners
incidence of sexual abuse
low socio-economic status
STAGE OF DIAGNOSIS
Tendency for later diagnosis
HEALTH BEHAVIOURS & LIFESTYLE CHOICES
increased rates of smoking
resistance to screening
HIGH RATES OF INCIDENCE & DEATH
4x cervical cancer incidence
2.5x rate of death

*Barriers to the Early Detection of Cervical Cancer*

The next important component of this review is a summary of the barriers to the early detection of cervical cancer for Aboriginal women. Given that cervical cytology screening is viewed as the single most effective tool for decreasing the incidence of cervical cancer, all of the barriers are discussed within this context (Band *et al.*,1992/1995; Canadian Cancer Society, 2004; Hislop *et al.*,1996; MD Consult, 2005; Ng *et al.*, 2004; Roos *et al.*, 1999; Strickland *et al.*, 1996). At this point, a gap in knowledge may be shown to exist on the nature of particular barriers for Aboriginal women in relation to the Pap test.

Barriers to participation in Pap screening, for all women, fall within the three main categories of cognitive barriers, emotional barriers, and socio-economic barriers (Alberta Cancer Board, 2001; Brentjens *et al.*, 2002; Calam *et al.*, 1999; Farkash, 2005; Healey, 2000). Similar to the general population, several studies found that Aboriginal women also experience barriers to screening participation related to body image (emotional barriers), barriers related to medical procedures, such as the actual processes and procedures of Pap smears (cognitive barriers), and barriers related to service locations (socio-economic barriers) (Band *et al.*, 1992/1995; Health Services Utilization and Research Commission, 1997; Hislop *et al.*, 1996; Sierra-Torres *et al.*, 2003; Solomon, 1998; Wilson, 2002). Additional barriers to screening for Aboriginal women that have been identified in the relevant literature include system barriers such as the inabilities of healthcare workers to recognize the potential concerns for Aboriginal women in relation to cervical health and culturally inappropriate delivery of health care services (Band *et al.*, 1992/1995; Hislop *et al.*, 1996; Sierra-Torres *et al.*, 2003; Solomon, 1998; Wilson, 2002). Just how barriers to screening participation, specific to all women, and barriers to screening participation, specific to Aboriginal women, interact to create an environment where Aboriginal women are less likely to participate in screening represents an area of knowledge that is not well developed within the literature.

### *Aboriginal Philosophies of Health & Wellness*

At this point, Aboriginal philosophies of health and wellness merit discussion in order to consider their important impacts on the sexual health and overall health of Aboriginal women. Although some aspects of this section may have been examined in chapter one of this proposal, they bear mention again in relation to the current and available literature in this area. A comprehensive understanding of Aboriginal culture and its influence on health within current health research usually acknowledges the need to recognize the diversity that exists within the Aboriginal population (Aboriginal Health, 1992; Alberta Health, 1995; Royal Commission on Aboriginal Peoples, 1996a). Although different cultural practices and tenets are attributed to different Aboriginal groups, many

Aboriginal peoples are said to exhibit similar beliefs and values in relation to health (Alberta Health, 1995; Health Canada, 2000; The Aboriginal Nurse, 2002a). This section provides an overview of the similarities toward health for Aboriginal peoples that are identified within current health research and literature and identifies the need for further understanding of Aboriginal philosophies of health and wellness.

Traditionally, Aboriginal peoples are described as having a holistic approach towards health, one that involves principles of harmony and balance. Essential to this view are the 4 aspects of the human (the physical, the emotional, the mental, and the spiritual) and the ideal to strive for balance within the individual, the family, and the community (Alberta Health, 1995; Bartlett, 2005; Goudreau, 2006; Roberts, 2005). Adjunct to the 4 aspects of the person and the desire to achieve balance is the belief that illness and disease are not necessarily a *bad thing*; rather, disease may be viewed as a sign sent by the Creator in order to help people re-evaluate their lives (Alberta Health, 1995; Dion Stout & Kipling, 1999). Of significance to any health research with Aboriginal peoples are the implications for this view toward disease and their apparent absence within the literature; therefore, from the perspective of the available published literature, it is difficult to determine if its impact on Aboriginal health is positive or negative. The story of a young Aboriginal woman visiting the Cross Cancer Institute in Edmonton, Alberta, for her initial visit depicts the complex nature of such views, the limited understanding of healthcare systems and staff of these views, and calls attention to the need for understanding the implications of such views from within cultural or Aboriginal perspectives.

> *A young Aboriginal woman had come to the Cross Cancer Institute for her initial visit. She had been experiencing a persistent sore throat and flu-like symptoms. What the staff discovered upon examination was a large open ulcer on the young woman's right upper chest that she had been bandaging as needed. When interviewed regarding the onset, duration, and accompanying symptoms of this ulcer – the young woman told the staff that she had been to a traditional healer earlier that year and that the woman understood this ulcer to be a result of her*

> *past lifestyle and the poor lifestyle choices she had made. In the end, the young woman had breast cancer and died from the disease a short two weeks later. What the staff understood to be an overt or serious sign of illness and what should have been acted upon by the young woman as soon as possible was further viewed as neglectful on the part of the healer with the information that the young woman felt she needed to simply endure this experience and learn from her past in order to get better.*

In hearing this story and similar experiences from my peers working with Aboriginal peoples, it becomes apparent that much learning and/or education is needed on the part of health research and health care systems to ensure that health care workers are adequately informed and armed with the skills needed to broach these situations. For example and in this instance, it is impossible to determine if the young woman did not have an adequate understanding of the traditional teachings she had received or if the teacher had in fact provided her with misleading information. Regardless of the particular circumstances of this sad story, it is important to note that the staff were unable to comprehend what may have contributed to the situation, much less fully consider any of the relevant cultural factors that may have affected its outcomes.

Within the literature, family structure is also considered to be an important cultural component of Aboriginal health and can be shown to significantly affect the health of Aboriginal women. For example, the traditional family largely positions Aboriginal women in a role that is highly valued and esteemed (Anderson, 2000; Royal Commission on Aboriginal Peoples, 1996a). Respect and reverence are only some of the values traditionally bestowed upon Aboriginal women for their abilities to carry life and to bear children (Saskatoon Health Unit, 1995). Many Elders will describe this gift of women as the gift to 'create' life. This moves the power of women well beyond that of "carrying" life and "bearing" children, both of which are elements of Western teachings as well; it explains how the concept of 'sacredness' is associated with the being of a woman. Today, many Aboriginal women find themselves in unfamiliar environments where traditional values and practices have often eroded and many of the traditional forms of birth control have been lost (The Aboriginal Nurse, 2002b). Further, birth control by external measures may be frowned upon by Aboriginal Elder members of society leaving Aboriginal women with fewer choices than non-Aboriginal women of mainstream society.

The shift from a subsistence economy to a cash economy and an increase in lone-parent families are just two of the circumstances that undermine the economic contributions that Aboriginal women make toward their families and communities (Anderson, 2000; Mitchell & Franklin, 2005; Moffatt, 2004; Van Kirk, 1980). This devalued position within society has been suggested to contribute to a poor self-esteem for some Aboriginal women and subsequently may have negative effects on the autonomy of many Aboriginal women (Larocque, 1993). In addition, both of these traits, a poor self-esteem and a loss of personal autonomy, are viewed as necessary pre-conditions for the many social problems that are reported to exist within Aboriginal communities such as sexual abuse and family violence (Bennett, 2005; British Columbia Ministry of Health, 2000).

Viewed as perhaps the most important aspect of culture that has affected the health of Aboriginal peoples, is the loss of culture itself (Royal Commission on Aboriginal Peoples, 1996a). For example, Health Canada (1996) recognizes culture as a significant determinant of health and that cultural survival is imperative for Aboriginal peoples. Goudreau (2006), in her thesis *Exploring the Connection Between Aboriginal Women's Hand Drumming and Health Promotion (Mino-Bimaadiziwin)*, mirrors these assertions through her findings that the relationships between Aboriginal health and healing are inextricably linked to cultural identity and Native expression. She states: "Drumming and singing are ways to express the importance of our culture, and for Aboriginal women to have a voice in this world. Thus, the process of discovering voice via hand drumming is about freeing Aboriginal women from suppression and empowering them to use their voices in a constructive manner. These women's voices are helping bring back balance and harmony to our communities" (Goudreau, 2006, p. 107).

Historical accounts of Canada's Aboriginal peoples reveal many of the historical assimilation policies of the federal government and some of the reasons for this loss of culture by Aboriginal peoples (Royal Commission on Aboriginal Peoples, 1996b). Examining some aspects of the loss of culture for Aboriginal peoples may provide insight into many of the values and health behaviours of Aboriginal women. For instance, traditionally the Aboriginal female's sex education began with the onset of menses and was taught by the grandmothers through the use of symbols and legends (Saskatoon Health Unit, 1995). The tragic systematic removal of Aboriginal children from their natural environments in order to "remove the Indian" from the Aboriginal population led to minimal contact with family members, a prohibition on the teaching and learning of traditional norms, and the subsequent decreased value of traditional norms and practices (Royal Commission on Aboriginal Peoples, 1996b, p. 52). This decreased value of traditional norms and practices is shown to have led to a loss of culture and those traditional health and healing practices that contributed to the health and wellness of Aboriginal peoples.

This review is not intended to be exhaustive of all the available literature on the many concepts discussed; however, it is sufficient to support a recognition of the boundaries that developing health knowledge in relation to Aboriginal women and cervical cytology screening must cross in order to provide accurate and useful information that will lead to improving the screening rates of Aboriginal women. A description of the significance of cervical cancer for Aboriginal women includes strong evidence of the existence of cervical cancer risk factors, the late stage at which diagnosis tends to occur for Aboriginal women, and the lifestyle factors of Aboriginal women that contribute to cervical cancer incidence. It is important to note the reciprocal relationship that is suggested to exist between the risk factors for cervical cancer and the lifestyle factors or health behaviours of Aboriginal women when considering the higher than mainstream rates of cervical cancer among this population. Cultural aspects within the literature that are considered important to the health of Aboriginal people, such as health beliefs, values, and attitudes were discussed and shown to draw a parallel between the poor health of Aboriginal peoples and the loss of culture which suggests the need to view health issues from the perspectives of the Aboriginal peoples. An overview of the barriers to the early detection of cervical cancer for Aboriginal women was provided (categories of emotional, cognitive, and socio-economic barriers) and the preventative measure of cervical cytology screening was cited as the primary intervention aimed at the early detection of cervical cancer; while, all of the barriers identified within the literature are placed within this context.

Based on current knowledge, it is probable that cervical cancer rates for Aboriginal women will continue to remain higher than the rates for mainstream Canadian women without increased cervical cytology screening. Designing purposeful interventions aimed at increased cervical cytology screening for Aboriginal women, must evolve from a comprehensive understanding of what Aboriginal women consider as significant in relation to their sexual health and how they make decisions regarding their sexual health, including the decision to participate or not in activities that lead to the early detection of cervical cancer. As well, a comprehensive description of the barriers to the early detection of cervical cancer for Aboriginal women requires that their perspectives of the underlying causes and meanings of identified barriers be obtained. Furthermore, cultural beliefs, values, and attitudes warrant strong consideration if new knowledge is to appropriately describe the contextual meanings of the barriers to cervical cytology screening for Aboriginal women.

Although the issues discussed within this chapter may be seen as a comprehensive review of the available literature regarding Aboriginal women and their participation in cervical cytology screening, the multitude of questions raised through the many simplistic explanations of Aboriginal health beliefs and knowledge suggest that large portions of current research fail to consider or address the influences of culture on Aboriginal women's decisions to participate or not participate in screening. Without this understanding, it is doubtful that the present information used to develop screening programs for Aboriginal women in relation to cervical cancer is sufficient and appropriate to provide service that is culturally informed and sensitive. For example, Hislop *et al.*, (1996) state that Aboriginal women reported that "prevention is not a meaningful concept to them" and that the "health promotion philosophy" of Aboriginal women is contradictory to the illness prevention stance that cervical screening education tends to form (p. 1705). Questions that arise from just these suggestions and which are largely unanswered within the literature are as follows:

1) What aspects of Aboriginal culture affect the utility of cervical cancer information for Aboriginal women?
2) Do Aboriginal languages allow for the expression of concepts that are related to cervical cancer and cervical cytology screening?
3) How are these meanings similar/dissimilar to western understandings of these concepts?
4) How does an Aboriginal woman view her body outside childbearing issues?
5) How does a devalued position within society contribute to the lack of knowledge that Aboriginal women have of Pap smear purposes and processes?
6) Do healthcare providers recognize the potential risks of cervical cancer for Aboriginal women?
7) Do healthcare providers understand the associated cultural barriers toward Pap screening such as body image?

These questions represent only a small sample of the questions that current research raises in relation to barriers to the early detection of cervical cancer among Aboriginal women. Identifying potential barriers without explicit knowledge of the implicit meanings that they represent for Aboriginal women likely will result in more data on Aboriginal health issues that does not accurately reflect how Aboriginal women see the issues of cervical cancer and cervical cytology screening. Further, cultural aspects that affect Aboriginal health is an area that has been approached by many researchers; however, evidence that the majority of the scholarly literature is written by non-Aboriginal scholars should call into question the reliability and comprehensiveness of the information that is published.

## *Nursing, Health Research & Cancer Literature*

> *The Cree terminology used when discussing someone having cancer was extremely interesting; the word used was almost always a variant of catching. Perhaps this is due to the Cree word for cancer, which is munchoosuk, a pluralized form of some kind of worm type organism and it would make linguistic sense to talk about munchoosuk in an external sense. The participants that I interviewed in English used the term 'cancer' and 'it', but there again, the term 'it' connotes a thing, an objectification of the disease, which isn't much different from how Non-Aboriginal English speakers refer to cancer. (Roberts, 2005, p. 112)*

Nurses, as primary care givers, often represent the initial point of access to healthcare for many Aboriginal peoples and play a substantial role in the development and delivery of health care services within Aboriginal communities (Dickson & Green, 2001; Vukic & Keddy, 2002). This necessitates that nurses possess both the ability to recognize potential health concerns for this population and the skills to address the issues (Browne & Smye, 2002). Possessing the ability to recognize cervical cancer as a health concern for Aboriginal women also requires the skill to address this sensitive and stigmatizing issue with Aboriginal women (Vukic & Keddy, 2002). Teaching nurses this skill is often left to the responsibility of the initial training program that the nurse takes, most of which do not have curricula or programming that is directed toward cultural training. Affecting this situation, therefore, is a concern for health policy that directs and provides the impetus for nursing practice.

Two recent studies conducted by Aboriginal Nurse scholars and fellow students of research have particular relevance to this project. Both occurred within the province of Saskatchewan, one with the Aboriginal peoples of Onion Lake and the other with the Woodland Cree of the Lac La Ronge band in Northern Saskatchewan. In completing a Master's of Nursing degree, Wilson (2002) worked with the First Nations peoples of Onion Lake, Saskatchewan, the band's health centre, attending physicians, and nursing staff. With the purpose to describe those factors that influence participation in Pap screening, Wilson (2002) interviewed eight First Nations women from Onion Lake and found that barriers to cervical cytology screening for these women include cultural health beliefs, feeling physically or psychologically uncomfortable, and feelings of embarrassment (p. 40). Similar to the findings of other research, Wilson (2002) concludes in her Abstract that the "identification of cultural beliefs, values, and customs among First Nations women is vital for the development of effective screening programs" (Alberta Cancer Board, 2001; Alliance for Cervical Cancer Prevention, 2004; Burhansstipanov *et al.*, 2001; Burhansstipanov & Hollow, 2001; Hislop *et al.*, 1996; Hodge *et al.*, 1996; Navon, 1999; Orians *et al.*, 2004; Ronson & Russell, 2003). Specifically and important to this project are the three themes that Wilson (2002) identifies as emerging in her research. Stated as providing a "description of the knowledge, attitudes and health beliefs of First Nations women" in relation to cervical cancer and screening, Wilson's (2002) three overarching themes are *'these are My feelings'*, *'this is what I know'*, and *' this is My culture'* (p. 25).

Reflected in the first two themes, *'these are My feelings'* and *'this is what I know'* is what may be considered common personal and community perspectives among many Aboriginal/Indigenous peoples - the values of respecting personal differences and the use of caution (First Nations, Métis and Inuit Steering Committee, 2004, p. 1-120). It was anticipated in this research that some of the participants, if not all, may identify and speak about their experiences as only one perspective and not necessarily the perspective of any other Aboriginal woman. As well, caution on the part of Aboriginal female participants regarding the researcher and the research topic was certainly a barrier that needed to be addressed during this project. Although the development of relationships was seen as integral to the success of this research, it was precisely the 'bridging' of those relationships that caused time and energy to be invested in the project on the part of the participants. This underscored the rationale and the need for me to work with 'Elder' women and communities during the development and implementation of my own research. Much of the data, I felt, would only be properly uncovered, interpreted, and understood if and when it was grounded in the context of cultural norms, teachings, and practices. As stated previously, this became possible through close and ongoing consultation with those community members who have expert knowledge of their culture and who possess the abilities to discern that which is reliably and culturally significant during the research process.

Equally important and of special note to the significance and purposes of this research study was what Wilson (2002) recognized through the development of her third theme *'this is My culture'*. She states the following:

> *Cervical cancer and cervical screening is a health issue that is not talked about among First Nations women. It's a personal issue that many First Nations women feel uncomfortable discussing as it involves mentioning the most private areas of a woman. Although, at times, it would seem that the described cultural beliefs could be barriers to care such as not talking about sex, or believing that surgical surgery causes a woman to lose her soul, the women seemed to be simply reporting their cultural beliefs. The women felt it was important for non-First Nations care providers to learn about their culture (Wilson, 2002, p. 52).*

That these women "seemed to be simply reporting their cultural beliefs", spoke to the need for this research that sought to provide health research, health policy, and health service providers with a description of Aboriginal women's experiences of cervical cancer (Wilson, 2002, p. 52). From within the lived realities of Aboriginal women and from the perspectives of Aboriginal women, this research developed new understandings of Northern Alberta Cree and Cree-Métis women's thoughts, feelings, and actions in relation to cervical cancer and cytology screening. Enabling the research and researcher to come to new and renewed understandings of Aboriginal women's sexual health and overall health, the processes of this research were engaged in the explication of the significance of culture to these important issues supporting the creation of new health knowledge in this area.

The second study, conducted by an Aboriginal Nurse, Roberts (2005), was done to fulfill a doctoral degree in the field of epidemiology. However, her work as a

Community and Public Health Nurse and Nurse Educator easily place the findings and utility of her research within the realm of nursing as the majority of recommendations are placed within this context. Entitled *Stories of Cancer Among the Woodland Cree of Northern Saskatchewan,* Roberts (2005) explored the views and meanings of health, illness, and cancer with participants from the five communities belonging to the Lac La Ronge Band of Northern Saskatchewan. Conducting narrative enquiry research, Roberts (2005) identified four major themes that emerged through her research; each of which may have relevance for this research project. These include the following: concepts of health and illness among the Woodland Cree show a complex intertwining of western and traditional belief systems; knowledge systems of the Woodland Cree represent the ways of knowing and being, including the seminal role that Elders have within the communities as teachers and knowledge keepers; cancer experiences of the Woodland Cree reflect physical, emotional, intellectual and spiritual aspects of health and illness; and the Woodland Cree traverse both worlds and possess the capacity to pick the best from both the western and traditional worlds (Roberts, 2005, p. 3/12). Providing support for the research framework of this project to view Cree and Cree-Métis Elders, teachers, and knowledge holders as integral to an exploration of those cultural norms, teachings, and traditions that affect, comprise, and support the sexual health of Cree and Cree-Métis women, Roberts (2005) stated,

> *Being an Aboriginal researcher does not necessarily imply easier access to communities. The dynamics of researching with Aboriginal communities are vastly different from researching within other environments. Community access is more process oriented and developing trust at the community level is a crucial factor. An important first step is initiating contact with key informants, who may also happen to be the Elders in the community. ...Elders are the knowledge keepers in Aboriginal communities and as such they should be the primary participants in any research project; they will provide a baseline reference point from which to proceed. They may also hold a position of such high esteem that if*

> *they do not agree with the intents of the research project, then the research will not be successful in meeting its objectives (p. 156).*

Further, Roberts (2005) indicated that there were clear advantages to doing this study as an Aboriginal researcher. These include established and trusting relationships with many of the participants of the study, a fluency in both her Native language and English, and an understanding of western sciences and her own cultural background which allowed her to more easily traverse both the western world and the Cree world. As determined in the first paragraph of this section and in consideration of the potential for stigmatization – related to pathological views of Aboriginal women and their health and the intimate nature of this research subject – the development of new nursing knowledge based on the lived realities of Aboriginal peoples and communities, may be best achieved with researchers who have established relationships and who possess personal and experiential knowledge of their culture. Nursing with non-western cultures, if the discipline is to contribute in meaningful and substantial ways to improving the lives and well being of these peoples, must conduct research that is capable of developing theory and knowledge that can ultimately affect and change appropriate health policy. As such, the development of culturally sensitive, relevant, and timely research that is beneficial to the Cree and Cree-Métis community required a framework that was grounded in the reality of the lived experiences of Cree and Cree-Métis peoples. This may best enable nurses to base their decisions within a holistic framework that places the Aboriginal peoples, such as the Cree and Cree-Métis in their real world and within their own realities.

### *International Research & Literature*

International research important to this project includes cervical cancer and cervical cytology screening literature on Indigenous women from Africa, Australia, India, Latin America, New Zealand, and the United States. The majority of this research, as well, tends to focus on women who are marginalized and considered to be the least educated in terms of the risk factors for cervical cancer and cervical cancer screening as a preventative measure of the disease (Mandelblatt *et al.*, 2001; Population Reference Bureau, 2004; Royal Thai College of Obstetricians and Gynaecologists & Corporation Cervical Cancer Prevention Group, 2003; Sankaranarayanan *et al.*, 2004; World Health Organization, 2002). Similar to much of the cervical cancer research and literature from Canada, Indigenous women often are the target population of sexual health education and programming that is designed to improve screening rates as they experience increased incidents and more subsequent deaths from the disease. Four major documents can be shown to summarize research, cervical cancer prevention, and screening among Indigenous and under-served populations. They include the following:

1) *Cervical Cancer Prevention: Issues in Depth* (Alliance for Cervical Cancer Prevention, 2004);
2) *Cervical Cancer Screening in Canada: 1998 Surveillance Report* (Health Canada, 2002);
3) *Cervical Cancer Screening in Developing Countries: Report of a WHO Consultation* (World Health Organization, 2002); and
4) *Preventing Cervical Cancer Worldwide* (Population Reference Bureau, 2004).

It is important to note that the majority of these four documents have been developed through partnerships at the international level. For example, the Alliance for Cervical Cancer Prevention consists of five international organizations such as the Pan American Health Organization and the International Agency for Research on Cancer. Decidedly, international health organizations have made it a priority to decrease future disease burdens from cervical cancer on national and international levels within third world countries and among Indigenous women. The objectives and purposes of these documents include mortality data from cervical cancer among different populations, regular reporting on screening activities among specific populations, recommendations for education and screening programming at international, national, and community levels, discussion on the affects and goals of health policy for cervical cancer screening and prevention, and current and future goals of research. For instance, found within the document, *Cervical Cancer Screening in Canada: 1998 Surveillance Report* (Health Canada, 2002), are reports on the screening activities from six provinces within Canada representing screening at the national level.

Implications for the significance of international health research and literature to this project included evidence of ineffective screening programming with marginalized and under-serviced populations, competing health problems among some populations, such as the Aboriginal population of Canada, and a current focus within health research on the role of HPV infection in the development of cervical cancer (Bowden *et al.*, 1998; Couzos *et al.*, 1998; Kattampallil *et al.*, 2001; Molodysky & Bridges-Web, 1996; New Zealand Nursing, 1987). For example, as noted in chapter one, the health problems of Aboriginal populations tend to be pronounced when compared to the rest of Canadians. That this affects and competes for health education and available program funding in relation to cervical cancer and screening activities for Aboriginal women appears to be justifiable in consideration of the statistics and reports on diabetes prevalence within these communities. As well, HPV infection, now commonly viewed as a significant indicator of future cervical cancer cases, is deemed especially important in relation to cervical cancer research with Indigenous women (Tiffen & Mahon, 2006). Discussed in further detail in the next section of this chapter, the current focus of international cervical cancer research on HPV infection prevention is shown to support the need for this research that intended to understand cervical cancer and screening experiences from the perspectives of Aboriginal women.

### *Current Trends in Cervical Cancer Research*

Much of the current research on cervical cancer from bio-medical perspectives focuses on the Oncogenic Human Papillomavirus infection (HPV) as an important precursor and predictor of cervical cancer (Bosch *et al.*, 2002; Brentjens *et al.*, 2002; Dell *et al.*, 2000; Ferenczy & Franco, 2002; Franco *et al.*, 2001; Hankins *et al.*, 1994; Healey *et al.*, 2001; Im & Monk, 2002; Lonky, 2002; Lytwyn & Sellors, 1997; Rohan *et al.*, 2003; Seppa, 2002; U.S. Preventive Services Task Force, 2003; Young *et al.*, 1997). HPV infection, largely considered a sexually transmitted infection or STI, has been documented to exist as early as the 1st century in the form of what is now more commonly known as genital warts (Bosch *et al.*, 2002; Franco *et al.*, 2001; Rohan *et al.*, 2003). More than 100 types of HPV have been isolated with at least 68 types having been linked to the incidence and development of cervical neoplasia (Bosch *et al.*, 2002; Brentjens *et al.*, 2002; Dell *et al.*, 2000; Ferenczy & Franco, 2002; Franco *et al.*, 2001; Hankins *et al.*, 1994; Healey *et al.*, 2001; Im & Monk, 2002; Lonky, 2002; Lytwyn & Sellors, 1997; Rohan *et al.*, 2003; Seppa, 2002; U.S. Preventive Services Task Force, 2003; Young *et al.*, 1997). Specifically, HPV types 16 and 18 have been linked through clinical trials to be strongly correlated with the development of invasive cervical cancer or cervical neoplasia at the level of CIN III (Bosch *et al.*, 2002; Franco *et al.*, 2001; National Cancer Institute, 2005; Rohan *et al.*, 2003; Tiffen & Mahon, 2006). In light of the recent biomedical research in this area, multiple sex partners and the early onset of sexual activity as strong predictors for the development of cervical cancer can now be seen as almost irrefutable fact. Evidence for this statement is easily found as a literature search reveals that some single studies are capable of referencing more than 200 related articles (Bosch *et al.*, 2002; U.S. Preventive Services Task Force, 2003).

These recent advancements in cervical cancer research have led to the development and availability of a vaccine that provides protection against the four specific types of HPV, two of which are reported to account for as much as 45% of HPV-linked cervical cancers (http://www.merck.com/newsroom/press-_releases/product/2006_0608.html). Already dubbed Merck's vaccine, this breakthrough in medical technology is expected to play an important role in the prevention of cervical cancer both prohylactically and therapeutically (Dell *et al.*, 2000; Lytwyn & Sellors, 1997; Rohan *et al.*, 2003). However and similar to many of the recent advances in modern medicine, it should be noted that for those countries where the most invasive cervical cancer cases are reported to occur, the availability of this vaccine is likely a long way off.

Particularly relevant to this research and the effects of this vaccine on cervical cancer incidence among Aboriginal women in Canada is the suggestion by some studies that "it is sadly rare for these patients to change their propensity to undergo additional future medical examinations and screening because of the same cultural, financial, or social barriers" (Lonky, 2002, p. 3). Moreover, a real potential exists for further stigmatization of Indigenous women and the associated risk factors for cervical cancer as important issues related to poverty and health service delivery may become even more significant in the prevention and diagnoses of cervical cancer in light of the fact that this vaccine has been approved for girls and women aged 9 through 26 (http://www.merck.com/newsroom/press_releases/product/2006_0608.html). Recognition of this increased potential for stigmatization in relation to cervical cancer and Indigenous women reinforced and supported further the need to conduct research such as this study that intended to describe and understand cultural knowledge and traditions that influence, support, and comprise the sexual health of Cree and Cree-Métis women across Northern Alberta.

### *Chapter Summary*

The purpose of this chapter was to present the findings from a literature review on what is known about Aboriginal women in relation to cervical cancer and cervical cytology screening and to discuss nursing and international health research that has particular relevance to the purposes and aims of this research. The work of two Aboriginal Nurse scholars and fellow research students was summarized and their relevance for this research project was outlined. This included Wilson (2002) and her identification of three themes that were suggested to resemble some of the concerns and aspects that arose during this research study. As well, Roberts (2005) study with the Woodland Cree of Northern Saskatchewan looked at the meanings of health, illness, and cancer and was discussed in relation to its support for the research framework that was utilized during this project. This included plans and intentions to work closely with Cree and Cree-Métis Elders and teachers in the development and conduct of the research and the importance of possessing established relationships and a similar cultural background

background in conducting research with Aboriginal women on a potentially sensitive and stigmatizing subject.

## CHAPTER THREE: RESEARCH METHODOLOGY & METHODS

In this chapter, I outline how an Indigenous research framework evolved during the study. This involved a bringing together of Indigenous principles and philosophies, and those tenets of Indigenous research and scholarship that were required to meet the specific criteria of the study. The framework included a blend of Indigenous methodologies that were congruent with the practices and protocols of the participants, with particular reference to the work of Meyer (2003) and Weber-Pillwax (1999/2003) and western methodologies, specifically drawing upon the hermeneutic and phenomenological interpretative approaches of van Manen (1991/1997). I begin by identifying the position from which I speak as a Cree-Métis person and by discussing ethical considerations which I believe are important for health research with Indigenous peoples generally.

### *Position From Which I Speak*

> *The notions of 'breeding' people and of valuing the 'white' portion over the 'Indian' portion of the identity are displayed blatantly in most examples of 'historical' writings and more subtly in contemporary writings about Indigenous peoples. (Weber-Pillwax, 2003, p. 123)*

I am a Cree-Métis woman whose Native family is from the small Métis community of Lac Ste Anne, Alberta. I grew up in an environment that I consider to have been rife with cultural conflict. The roots of this conflict are the non-acceptance of our Native heritage by non-Native members of my family and Native members of my family, including my Native Father and Grandparents. Both the seemingly non-acceptance of our Native heritage and the conviction with which I was taught to be proud of my Native ancestry ultimately led to a source of confusion regarding my own identity that has taken me most of my adult life to understand. What I had considered to be my identity was entwined with Cree and Cree-Métis philosophies and ways of being; however, I did, in fact find that developing and conducting this research helped me to gain a clearer understanding and insight of my non-Aboriginal heritage. This was due to the nature of the research and what I had learned about the similarities and differences between my Mother's experiences and my Father's experiences. I found that the more I understood these similarities and differences, the more I would come to appreciate them.

The significance of these experiences, with regards to this work, were realised as I underwent transformations of my own identity. I also found that there were moments during the research processes where the women were asking themselves the same questions and coming to similar conclusions – ultimately, we learned to further appreciate our histories together. In learning together and changing together, we recognised the similarities and differences in one another and came to a clearer understanding of one another's ways of thinking and being. Our differences seemed to dissolve and our similarities drew us closer together as our relationships deepened.

The one constant that was shared between the women and me was our feeling and belief that we needed to personally contribute in meaningful ways to improving the lives and well-being of our communities. Feeling trapped or perhaps chained by the emotions and fears associated with an illness such as cancer and our situated-ness between the western world and our Indigenous world, we were grounded in this work by the possibilities of gaining a further understanding of ourselves and our place in the world as Indigenous women and females. Caught, as we are, between the western world and the Indigenous world when we undergo treatments for disease and illness only emphasized for us the need to have access to and to understand the cultural knowledge and wisdom of our ancestors. In this place, between the 'white' world and the 'Aboriginal' world, I learned that the possibilities for understanding the significance of culture in the health and wellness of women, families, and communities were infinitely greater *because* there are differences, rather than *despite* the differences.

### *Definition of Terms*

1) "Western" within this research refers to those ideas and practices which emanate from historical European modes of thought or ways to view the world and is used synonymously with 'mainstream'. – "to represent an archive of knowledge and systems, rules and values extracted from and characteristic of Europe and the Western hemisphere" (Smith, 1999, p. 42)
2) Elders, teachers, or knowledge holders are those who are recognized by one or more Aboriginal communities or within their own community as possessing specialized knowledge related to beliefs, values, spiritualities, histories, cultural roles, traditions, and other forms of teachings associated with particular cultural or tribal groups.
3) Aboriginal female participants refers to those women who identify themselves as having Aboriginal ancestry, or within this research, refers to those women who have self-identified as Cree and Cree-Métis from across Northern Alberta.
4) Indigenous/Aboriginal/Cree/Cree-Métis traditional/cultural/special knowledge is the knowledge and teachings passed from our ancestors through oral transmissions, ceremony, and practice that support and form the basis for cultural norms, traditions, medicines, and practices.
5) Aboriginal language within this study refers to the Cree language.
6) Cervical cancer experience includes a past or present diagnosis of cervical cancer and the treatment of the disease, which may or may not be recognized by the public health service delivery system. Treatment may include or refer exclusively to the use of traditional medicines, practices, and ceremonies.
7) Cervical cytology screening or what is commonly known as the Pap test refers to the procedure and associated education that clients receive related to the procedure, including its processes and purposes.

### *Ethical Considerations in Research with Indigenous Peoples*

> *The researcher is accountable for the effects of the research on the lives of the participants, and indeed can also be held accountable for impacts on the lives of everyone in the community. This means that in choosing research methods, I, as researcher, must consider carefully not only the possible effects of my whole research project, but also the effects of each specific research method.... (Weber-Pillwax, 2004, p. 81)*

Indigenous researcher, Humphery (2001), explored the recent reform of research frameworks in a context of the Aboriginal peoples of Australia. She stated, "[I]t is argued…that efforts to reform the practices of mainstream Indigenous health research since the 1980's have oscillated between taking concrete steps towards actually changing research practice and placing too great a reliance on written guidelines and positive rhetoric" (p. 197). The basis for much of this reform is likely embedded in the distrust of Indigenous peoples regarding the outcomes of research and the practices of researchers, such as the tendency to obtain data and never return the benefits to the community or peoples involved (Ermine *et al.*, 2004; Royal Commission on Aboriginal Peoples, 1996a; Smith, 1999).

In response to these issues and concerns, research institutions, Aboriginal organizations, and even particular Indigenous Nations have developed guidelines intended to provide the rules for ethical and responsible research with Aboriginal peoples and communities (Canadian Institute of Health Research, 2007; Kahnawake Schools Diabetes Prevention Project, 1996; National Aboriginal Health Organization, 2002; Royal Commission on Aboriginal Peoples, 1993; Saskatoon Aboriginal Women's Health Research Committee, 2004). However, it should be noted that the overwhelming bulk of research on Aboriginal peoples has been conducted by non-Aboriginal peoples and/or people from outside these Aboriginal communities. Although this does not absolve Aboriginal researchers or those doing research within their own communities, of ethical responsibility, it does indeed suggest that research performed by 'outsiders' was the impetus for the reform and change within mainstream health research. Moreover, it was precisely similar concerns on my part as researcher – the protection of participant anonymity, the creation of safe learning environments, and the need to avoid any further stigmatization of Aboriginal women – as well as the nature of the research topic that led to the development of the research framework for my work to be grounded in Indigenous principles and philosophies. Accordingly, the building of trust represents the interface at which the successful outcomes of this research became possible.

### *Developing an Appropriate Methodology*

> *...the methodology displayed during this research arose as a natural outcome of interactions between Indigenous persons within the context of Indigenous communities.... I did not decide ahead of time what methodology I intended to use; I simply knew what approach I had to follow in order to be respectful and to find Indigenous persons who would be interested in working with me on a topic that they too were interested." (Weber-Pillwax, 2003, p. 29)*

Key considerations of the research methodology were the steps and processes necessary to work with Northern Alberta Cree and Cree-Métis women, Elders, and communities on a culturally sensitive and significant topic – the sexual health of Aboriginal females. For example, Smith (1999), an Indigenous researcher from New Zealand, states that methodology is important because it frames the questions being asked, determines the set of instruments and methods to be employed, and shapes the analyses (p. 143). Further, Smith (1999) finds that, necessarily, Indigenous methodologies are often a mix of existing methodological approaches and Indigenous practices. The methodology of this research sought new understandings of Aboriginal female sexual health and overall health from contemporary Elders and traditional teachers from across Northern Alberta with the goal to 're-contextualize' our understanding of the cervical cancer experiences of Cree and Cree-Métis women into one that fit within 'Aboriginal lived realities'. Understanding sexual and overall health from within a Cree or Cree-

Métis context or from these specific 'Aboriginal' perspectives therefore required a methodology that could intertwine different research approaches with relevant and related cultural norms, values, and practices.

Paramount to an accurate description of Aboriginal cultural norms and practices in relation to Northern Alberta Cree and Cree-Métis women and sexual health was a specific criterion that also supported and ensured the reliability and validity of the results themselves. The specific criteria or needs of the research project included an approach that supported the following:

1) The establishment and support of trusting relationships;
2) The development and maintenance of safe learning environments;
3) Methods relevant to the culture of the community and acceptable to the community;
4) A move away from current pathologizing views of Aboriginal women;
5) The protection and anonymity of participants within and outside their communities;
6) A recognition of the expertise and knowledge of the community;
7) An acceptance of alternative ways of knowing and being as elements of knowledge creation and/or re-creation;
8) Giving credit to the specific sources of knowledge;
9) Returning what was learned to the participants and community for the benefits of Aboriginal women and families; and,
10) Enabling the research and its processes to go through their natural progression within time as existing relationships and new relationships were built upon new understandings of Aboriginal perspectives of health.

### *Indigenous Principles & Philosophies*

The core features of Indigenous research identified by Martin (2002) and the key issues to be considered in the development of Indigenous research methodologies identified by Weber-Pillwax (1999) envelop the theoretical perspectives and philosophies upon which this research framework was built. Both were applicable to this research and its methodology as I found each feature and key issue to either represent, coincide with or contain significant elements of the principles and philosophies of the research participants and their communities. Martin (2002) identifies the following as the core features she considers to be integral to an Indigenous research methodology:

1. Recognition of our worldviews, our knowledge, and our realities as distinctive and vital to our existence and survival;
2. Honouring Aboriginal social mores as an essential process through which we live, learn, and situate ourselves as Aboriginal people in our own lands and when in the lands of other Aboriginal people;
3. Emphasizing the social, historical, and political contexts which shape our experiences, lives, positions, and futures;
4. Privileging the voices, experiences, and lives of Aboriginal people and Aboriginal lands; and,
5. Identifying and redressing issues of importance for us. (Martin, 2002, p. 5).

Weber-Pillwax (1999) outlines those principles that she identifies as "significant guides in the planning and implementation of research projects that involve Indigenous participants" (Weber-Pillwax, 2003, p. 41). They are as follows:

1. All forms of life must be respected as being related;
2. The research must benefit the community;
3. The research must be grounded in the reality of the lived experience;
4. Indigenous methodologies must provide the foundation for theoretical development;
5. Transformation and process are central elements of the research; and,
6. The integrity of Indigenous peoples or communities needs to be respected (Weber-Pillwax, 1999, p. 23).

Additionally, and in harmony with many of the insights gained during this study, research and/or theory with regards to the health and wellness of Aboriginal peoples must recognize and include avenues and strategies for healing from trauma and enforced marginalization. Also cited by other Indigenous researchers and scholars as vital to Indigenous health and wellness, providing such avenues and strategies for healing was in fact viewed by the Elder participants of this research as an integral component of traditional teachings, medicine, and knowledge (National Aboriginal Health Organization, 2008; The Aboriginal Healing Foundation, 2004). As reflected in the stories of the women Elders, culturally respectful, relevant, and ethical research that intends to work toward the improved health and wellness of Aboriginal women is therefore inadequate or incomplete if it fails to acknowledge or address this need for healing.

Throughout this document, I have referred to the building of trustful relations as key to the success of this research. I cannot overstate the importance of building these relationships of trust in consideration of the successful outcomes of this research or indeed, of any research with Aboriginal peoples. Further, ongoing discussions with Aboriginal women, Elders, and community members in all facets of my life and professional career reiterate the need and value of trust in relation to the health and healing concerns of Aboriginal peoples in general. Without the building of trust in the research relationships, it is not likely that many of the Elders and women in this study would have agreed to participate. No amount of time and energy spent in other forms of preparation and planning would have granted a similar level of commitment to this research as was shown by these Elders and women. Moreover, without their shared beliefs in the potential benefits of the project for other Aboriginal women and their health, the research would have failed to articulate the related issues of these Cree and Cree-Métis women from their own perspectives (Martin, 2002; Weber-Pillwax, 1999).

### *Tenets of Indigenous Scholarship*

Foundational to the paths of this particular research were several principles or tenets of Indigenous scholarship. As a novice researcher with Aboriginal peoples and communities, the role and meanings of 'relations' has remained central to all the activities (methods) and provided the contexts (methodology and epistemological frame) for my own learning. Hawaiian researcher, Meyer (2003), alludes to the complexities of relations within Indigenous research when she states: "as we develop a deeper experience of our own epistemology…. We're heading into our own radical remembering of the future" (p. 249). Indicative of the multifaceted relations, relationships, and inter-relationships that are integral to Indigenous knowledge(s) and knowledge creation, Meyer (2003) is at least referring to ancient knowledge systems as foundational in relation to contemporary Indigenous cultural realities. Aboriginal researcher, Wilson (2003), also characterizes this central role of relation in Indigenous research. In his discussion on Indigenous ways of discovery and knowing, Wilson (2003) describes the concept of 'relationality' as the lens through which to view or the idea that "all things are related" to one another (p. 87). Wilson (2003) further emphasizes that relationships for Aboriginal/Indigenous peoples "do not merely shape reality, they *are* reality" (p. 3/4). Throughout this work, the significance and meanings of 'relations' were reflected in the principles of the research methodology, its underlying assumptions, descriptions of the processes and content of the research, and the position of the researcher. Further, these relationships are shown to be necessary elements for my own capacity as the researcher to understand these and arrive at logical and reliable analyses and conclusions.

### *Principles as key elements for learning*

> *Respect is more than just saying please and thank you, and reciprocity is more than giving a gift. According to Cree Elders, showing respect or "kihceyihtowin" is a basic law of life. Respect regulates how we treat Mother Earth, the plants, the animals, and our brothers and sisters of all races…Respect means you listen intently to others' ideas, that you do not insist that your idea prevails. By listening intently you show honour, consider the well being of others, and treat others with kindness and courtesy. (Steinhauer, 2002, p.86)*

Respect, reciprocity, and relationality – or the three R's[14] as principles of research with Indigenous peoples – may be collective values or universalisms in the Indigenous world. As tenets of Indigenous scholarship, they not only represent the principles that guided this research and its processes, but also underlay the successful outcomes of working with the participants and their communities. Indigenous scholars Cardinal (2001), Steinhauer (2002), and Weber-Pillwax (2001) talk about maintaining these principles as a way of honouring Indigenous peoples in research and describe them as foundational elements of Indigenous research.

While definitions of respect, reciprocity, and relationship building may vary within different cultural contexts, my research showed me that these principles were both elements of the process and the outcomes of the process. It was through participation and interaction with all research participants that this realization evolved. For example, my preparation and participation in protocol and ceremony with the Elders demonstrated respect for their time and teaching. Aboriginal scholar and researcher Graveline (1998) makes reference to "the fundamental law" of reciprocity (p.62), and in my work with Cree and Cree-Métis Elders and women, I found reciprocity to be instrumental in the building of our relationships. Elder Isabel Auger spoke directly to the meaning and significance of this concept in the lives of Cree people, describing the importance of following cultural protocols in the expression of the fundamental law of reciprocity:

> *[W]e got our tobacco and our print here, that's our protection. From all, the tobacco is number one. What we take from the ground or from the willows or the leaves.... We ask for it when we put down our tobacco. If it's this and that, we ask for it. When we take something, we have to put something back. You take something, you have to give something back for that medicine. It's always*

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[14] See Kirkness & Berhardt (1991) for a description of the four R's – respect, relevance, reciprocity, responsibility – that they describe as key considerations in the development and conduct of research regarding higher education and Aboriginal peoples.

> *something, we have to carry a little pouch in our purse to ask Mother Earth, can we use it?*

Through personal preparation and adherence to cultural protocols – i.e. use of tobacco and cloth – I was able to engage with the Elders in a respectful manner and establish and facilitate the processes required to ensure a culturally safe and appropriate environment for teaching and learning traditional cultural knowledge. Through these processes and personal efforts, research relationships were established on the basis of respect and reciprocity. Further, while retracing the steps and activities of the project, I found that these principles of Indigenous research were most fully expressed in the successful outcomes of the research process. Inherent to my learning from within an Indigenous context, the principles of respect, reciprocity, and relationship building were also foundational to the processes that unfolded.

### *The circle as a symbol for learning*

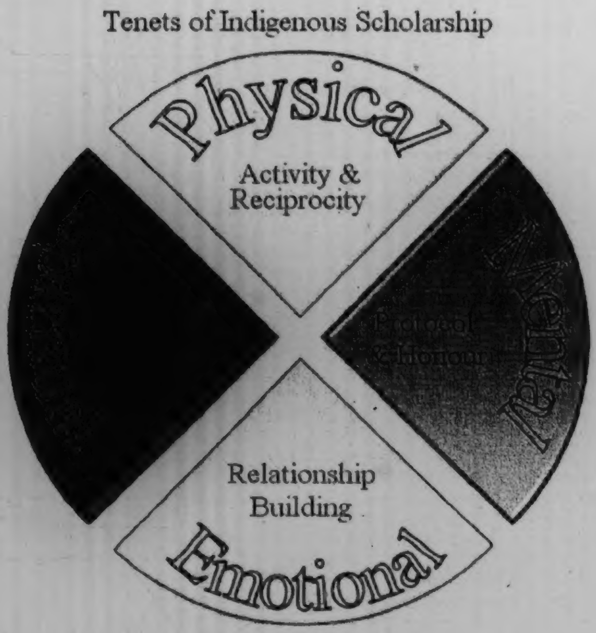
> *You have noticed that everything an Indian does is in a circle, and that is because the Power of the World always works in circles, and everything tries to be round. ...: Everything the power of the world does is done in a circle. The sky is round and I have heard that the earth is round like a ball and so are all the stars. The wind, in its great power, whirls. Birds make their nests in circles, for theirs is the same religion as ours. The sun comes forth and goes down again in a circle. (Neihardt quoting Black Elk, 1932/1959, p. 164)*

Elders, as the keepers of traditional knowledge in Aboriginal societies use stories and symbols in their teaching. The circle (often illustrated in terms of an Aboriginal symbol of health and wellness – the Medicine Wheel) is understood in terms of harmony and balance (First Nations, Métis, Inuit Steering Committee and Working Committee, 2004, p. 1-125). The philosophies and teachings held within the Medicine Wheel reflect the four aspects or dimensions of humans, which include the physical, the mental, the emotional, and the spiritual. Also reflecting the four seasons, directions, races, elements of the earth, life cycles, and much more, each of these aspects contain their own teachings and is an interconnected part of the greater whole. Seen as being in a constant state of change or 'flux', Ermine (1995) describes this interconnectedness and wholeness as Aboriginal peoples' "fundamental insight…that all existence was interconnected and that the whole enmeshed the being in its inclusiveness" (p. 103).

The underlying principles that guided the activities of this research, and their role in the processes that ensued, evolved and built upon one another in a cyclical pattern. This may be further understood in terms of 'relations' or the relational nature of these principles to each other as parts of a greater whole. Viewed from within the circle, the underlying principles of this research – respect, reciprocity, and relationship building – illustrate the idea of interrelatedness and demonstrate the principle of a coming together of things (First Nations, Métis, Inuit Steering Committee and Working Committee, 2004, p. 1-123). As well, preparation in following the practices and protocols of Aboriginal peoples played an essential role in exercising these principles throughout the research. In working with Cree and Cree-Métis women and Elders on a topic of cultural significance that has the potential to import further stigma and harm, participating in activities inclusive of these underlying principles reinforced them as essential or integral to successful processes and outcomes. Moreover, and in reflecting upon these principles of Indigenous research, this enabled the research and researcher to actively acknowledge that "[n]othing we do, we do by ourselves…. " (Graveline, 1998, p. 56).

Working from within this framework opened the doors to learning in an Indigenous context. Graveline (1998) describes working from within this context as the movement to a paradigm that "challenges us to shift from the linear, cause-effect models of thinking…and to embrace the circular ever-evolving dynamic" that is reflected within the perspective of holism (p. 75). Figure 2 depicts the principles that guided this research as interrelated and essential to the processes that unfolded during the study. Viewed from within the circle (or Medicine Wheel), the research gained a fuller understanding of how these underlying principles and the ensuing processes would work together to form a greater whole. My purpose in using the Medicine Wheel is to show the inter-relational nature of the concepts and processes that unfolded during the research. However, and similar to what Calliou (1995) states, "I am no Medicine Wheel expert, but more and more I appreciate its internal wisdom and its ability to explain relationships" (p. 51).

Figure 2: Tenets of Indigenous Scholarship


Tenets of Indigenous Scholarship
Physical
Activity & Reciprocity
Mental
Protocol & Honour
Emotional
Relationship Building

*This circle or Medicine Wheel illustrates the relational nature between underlying principles of Indigenous research and their role as key elements that needed to be present in order to work from within this context.*

### *Recurring Themes of Indigenous Research*

In the previous sections I alluded to several underlying assumptions of the Indigenous research methodology that evolved during this study, such as the concepts of holism and balance. From within the context of this research, four recurring themes may also be considered as necessary and essential elements to the methodology. As the four recurring themes emerged – ceremony, shifting, transformation, relationality – I found further evidence for these processes as indicative of Indigenous research methodologies (Martin, 2002; Weber-Pillwax, 1999/2003).

### Ceremony

Ceremony in this research took on multiple meanings and involved concrete and mimetic experience. Ceremony in the form of rituals followed the cultural protocols of the women and communities I was working with, such as the offering of tobacco to Elders and the gifts to the women. These kinds of activities respected directly the shared customs and practices of a group of Aboriginal women. Ceremony as a process and mimetic experience in my own learning as researcher also took place. Weber-Pillwax (2003), talks about ceremony as "the means that enable us to reach other states of being where we can realise these experiences" (p. 181). Similarly, Gunn Allen (1986) writes, "[A] raising or expansion of individual consciousness naturally accompanies this process. The person sheds the isolated, individual personality and is restored to conscious harmony with the universe" (p. 62).

During my writing, I struggled in trying to understand how the activities and processes I had gone through in relation to working with the female Elders and traditional teachers was in fact directly related to the work of interviewing the women who had experienced cervical cancer. As I traveled to Calling Lake and Sandy Lake with my friend and mentor, Dr. Cora Weber-Pillwax, experiencing ceremony as a process became another layer or an experiential form of my learning during this research. This creation of knowledge through experience is best reflected in the following excerpt from my field notes:

> *Cora and I went to her community of Calling Lake, Alberta, with a purpose of going through and discussing some of my writing. We arrived in Calling Lake and had some tea before deciding to go to Sandy Lake to visit Alice Reid – an Elder and traditional teacher who participated in my research. Cora had been meaning to visit her aunt Alice for some time and I wanted the opportunity to bring her up to date on my research. I brought some sage with me that grows in my backyard and Cora decided to take a small gift as well. After we arrived, Alice served us supper and we began to talk about her experiences as a nurse in Aboriginal*

*communities. I usually have so many questions for Alice, but felt that my presence in her home on a social visit should limit what I was asking of her. I remembered something she had said during the Elder gathering that helped me as a nurse in working with patients who were near death and dying. She talked about the spiritual dimension of human beings and how you are never closer to that dimension of another person than when they are near death. For Alice, this naturally seemed to lead the conversation to the kinds of transformations she has experienced in her lifelong learning as an Aboriginal person and knowledge holder. Upon reflecting on her choice of conversation and knowing that I see transformation as a main theme or process in my learning, I realise that Alice's conversation around that very topic is probably more than mere coincidence.*

*The next day, Cora and I began to look at some of my writing and we talked at length of the struggles I was having with the particular chapter. I wondered about my use of the Medicine Wheel as a way to illustrate what I had been learning. I also had been wondering for some time how all the activities of my research and the processes I had been trying to get through, such as where my work with the Elders fit into the work that I had done with the women and how the main themes of my learning in the research – ceremony, shifting, transformation, relationality – were actual processes of learning. Then we started to talk about ceremony and its different meanings. I began to more fully understand how ceremony can refer to participating in activities or performing a ritual, but also it can be a process that one experiences in all the dimensions of their being. At the end of the day, I started to cry. I finally knew that I understood some of what I had been struggling with so much. Then Cora said that what I had experienced this weekend was indeed a ceremony – going to see Alice, Alice's reflections and experiences with transformation, offering her sage and gifts, smudging before looking at my writing with Cora, shifting my understanding of how I thought about the processes of my research, and a transformation of me through what I had learnt –*

*gaining new understanding and knowledge really is a physical, mental, emotional, and spiritual journey!*

Throughout this experience, I was participating in the activities that would lead me to new understandings. The physical part of me traveled to other places. Mental preparation for what I was going to learn took place as I thought about the offering I would take Alice and talked with both her and Cora throughout the trip. As a Cree-Métis person, learning on a deeper and more meaningful level is often an emotional experience that requires a shift in thinking or consciousness. A shift in my thinking was precipitated through physical, mental, emotional, and spiritual preparation, such as the smudging of sweet grass. All of these experiences, together, led me to new understandings and the creation of new insights or knowledge within me regarding the connections between the work with the women and the work with the Elders.

### *Shifting*

Graveline (1998) talks about tapping into 'right-brain' energies as another means of learning. She explains that this capacity is taught through learning to move to another state of consciousness and finds that, "through this process we are able to find our personal meaning from any educational experience" (Graveline, 1998, p. 77). As an Indigenous process, a shift in my thinking, and at times, consciousness worked to change my perceptions through which new insights were realised. In my learning, the manifestations of these shifts were often visions and dreams that were precipitated through ceremonial events, such as entering the sweat lodge. The sweat lodge is envisioned to represent the womb of Mother Earth and, "like mother's womb, is a place of transformation" (Anderson, 2000, p. 73). This was also alluded to in the previous discussion regarding ceremony as a mimetic experience and one process through which I was able to understand new relationships between the work with the Elders and the women's stories.

Weber-Pillwax (2003) explains how a shift within oneself can precipitate new insights. She states, "When our perceptions are blocking our development in consciousness, we need an external force to create a shift within us, enabling us to see from a different perspective, the only requirement from us is our willingness and intentions to let something new enter into and interact with our beings" (Weber-Pillwax, 2003, p. 69). Concrete evidence of the results of a shift within myself or of my consciousness were realised in the development of my dissertation outline and large pieces of my writing. As a student and learner, I too, had to go through the mental exercise of bringing together and writing about the main points of the research. However, I did participate in ceremonial activities and then wake up one morning after a dream and was able to quickly and accurately develop the outline for this work several months prior to analysing the data and writing the chapters. Although I have strayed from this initial outline, what that experience did was provide me with important direction towards some of the more significant elements of the research. In fact, each time I felt blocked or 'stuck' during this research, I took some type of action to 'create this shift within myself'. Much more than a mental exercise, my intentions were always to draw upon my spiritual connections and dimensions as an Aboriginal/Indigenous being and the inter-relationships that exist therein. It is from within an Indigenous being's relationship to this source of power that new windows of opportunity and experience arise and new knowledge is created. Within an Indigenous research methodology, the measure or test of knowledge is experience (Weber-Pillwax, 2003).

Experiencing a shift, in relation to place and land also contributed to my learning during this research. Prior to completing the analysis of the women's stories and Elder's gathering, I attended a cultural camp. Through participating in ceremonial and traditional activities at this camp, I would experience a shift that enabled me to better understand the role of relationships in Cree and Cree-Métis health and wellness. This fuller understanding gradually became more meaningful in relation to my research data and the relationships and inter-relationships of health and wellness that were manifest in the women's lived experiences and Elder's stories. The following excerpt is taken from field notes:

> *Upon our arrival to the camp some of the men had killed two elk. It was the women's job to cut the meat for drying and smoking. As we did this and the women began to laugh and tell stories, a feeling of well being swept over me. Some of the stories provided traditional teachings that were directed towards the younger women in attendance, myself included. Others were stories of families and people who were known to some of the women.*

In reflecting upon this experience, my own sense of well being was tied to this space (of relationships and inter-relationships) that I had entered through the activities that we were doing. Preparing this meat with the women that we would later eat together while telling stories about the teachings that we knew and the people that we knew would later find further significance during the analyses of the women's experiences and the Elder's gathering. The women would all talk about their own sense of well being as being enmeshed within the relationships that they held with others and in relationship to themselves and their philosophies as Cree and Cree-Métis peoples.

## Transformations

Weber-Pillwax (1999) states that transformation and process are central elements of Indigenous research. Throughout this research, I found that asking myself questions related to my own transformations was often a way of gauging my success. Questions such as – What's happening to me? How am I changing? What am I thinking? – often led me to new insights regarding the women and their experiences. Much of the transformation that I was consciously aware of during this research was related to the further understanding that I now have of Cree and Cree-Métis women and our common experiences as Aboriginal women. Most of us tend to experience racism, violence, abuse of some nature, a deep sense of loss in relation to culture and language, and the need to understand ourselves as Indigenous beings. Similar to what Weber-Pillwax (2003) found in her research, I found that the transformations of the women and myself throughout the research processes, "occurred as a result of the intense and deeply personal nature" of this research (p. 39). For example, although the research interviews focused on the women's cervical cancer experience, the nature of the questions, our similar orientations to the world, and the building of our relationships based on principles of respect and reciprocity supported and enabled the discussions to be reflective. In this way, transformations within ourselves, myself as the researcher and the women, developed through the research and its processes. Specifically, this was particularly apparent in relation to our discussions and reflections regarding sexual activity and its relationships to the development of cervical cancer as the women all stated that they had gained further understanding of the role that HPV may play in cervical cancer illness.

### *Relationality*

> *Relationship is the critical factor in the development and establishment of respectful Indigenous research projects. There is always a relationship between researcher and area of research, but when the research topic is embedded within human beings, then methodologies or strategies must be designed within the cultural parameters and definitions of respectful relationships.... Indigenous forms of research involve the establishment of particular and relevant forms of interrelationships among all living things connected with the research itself. (Weber-Pillwax, 2003, p. 38)*

During an interdisciplinary conference for Aboriginal health and education practitioners at the University of Alberta, Elder and educator John Crier spoke about the important issues facing students and their communities. He asked students at the gathering to ask themselves in their work, "What concepts resonate with you as an Indigenous person?"[15] What immediately came to my mind in relation to this research were the central roles of relationships in all facets of the project. As I developed relationships with the women, Elders, and communities, the work would become more meaningful for me through their recognition of the potential benefits of the work for Cree and Cree-Métis women and their communities. As I began to collect and analyse the data, I would consistently find that locating the relationships between the women's stories and the cultural philosophies of the women Elders would enable a deeper and more meaningful understanding of the women's lived experiences regarding health and illness. In addition, as the relationships between the work with the women and the work with the Elders would unfold, a distinct cyclical or spiral pattern of what I was learning emerged as each phase of the research would build on the previous insights that were gained. This became a source of validation regarding the time and energy that was spent on relationship building – a cultural tenet and value embedded in Indigenous research and Aboriginal philosophies – and how this was critical to the success of the research. As well, prior to attending a gathering of Aboriginal student researchers I was asked to think about the question, "Where is the you in your research?" In my own reflection upon this question, I found that the women who are my relations – my mother, aunties, grandmothers, and sisters – are much more than the sum of their health and illness experiences. They are, in fact, the teachers of the 'lens' through which I make sense of my own health and illness experiences. The ways in which these teachers are able to provide this 'lens' is through their own sources of these teachings – such as knowledge gained through their experiences, teachings from old peoples, the world around us, and the Creator. Weber-Pillwax (2003) talks about these 'origins' of knowledge for Indigenous peoples when she states, "…unknowable sources [our ancestors]…are the origins or starting point of the knowledge that is available to us" (p. 11).

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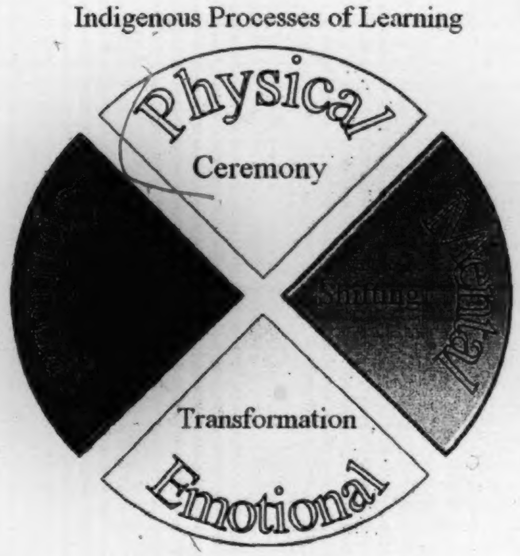
[15] Personal Communication – Elder John Crier. December 1, 2007. Interdisciplinary Aboriginal Professionals Gathering, University of Alberta, Edmonton, AB.

In summary, ceremony, shifting, transformation, and relationality have been shown to emerge as the necessary elements of the Indigenous research methodology that evolved during this project in relation to my learning. Ceremony included concrete and mimetic experience. A shift, sometimes to another state of consciousness and in relation to space would help me to gain insights regarding the significance of the principles of the research. Transformation was talked about and suggested to occur during some of the activities of the research that supported and enabled reflection on what was being discussed and learnt, such as the women and their views of the role of HPV in the development of cervical cancer. As well, relationality and relationships were talked about as playing a central role in the development, conduct, and outcomes of the research. Figure 3 illustrates the relational nature of these recurring themes throughout the research and emphasizes the circular or spiral pattern of learning within an Indigenous context.

Figure 3: Indigenous Processes of Learning



*Ceremony, Shifting, Transformation, and Relationality were recurring themes that emerged during the research. Representing elemental processes of my learning, their interconnectedness reinforces the circular nature of learning from within Indigenous contexts.*

*The Role of the Researcher in Indigenous Research*

> *The source of a research project is the heart/mind of the researcher, and 'checking your heart' is a critical element in the research process. The researcher ensures that there are no negative or selfish motives for doing the research, because this could bring suffering upon everyone in the community. A 'good heart' guarantees a good motive, and good motives guarantee benefits to everyone. (Weber-Pillwax, 2003, p. 42)*

Referred to earlier through the work of Weber-Pillwax (2003) wherein she states that respectful Indigenous research projects always possess “a relationship between the researcher and area of research”, relationships and my role in these relationships was a “critical factor” in the success and outcomes of this research (p. 38). Central to this success and reflected throughout the discussions were my motives for the development and carrying out of this study and my role as the researcher. Within the introduction of this work, I stated that ‘a resounding absence of Aboriginal women’s voices within a potentially stigmatizing and particularly intimate area of health research, such as cervical cancer and cervical cytology screening, became a source of angst for me’. The lack of culturally appropriate views of Aboriginal female sexual health within the relevant research and literature, coupled with my experiences as a health practitioner were what led me to the primary motivation for this research: articulating the wisdom and enabling the voices of Aboriginal women to be heard in relation to their sexual health. Perhaps at ‘the heart’ of this motivation is the underlying tenet of Aboriginal/Indigenous philosophies and research described by Meyer (2003), Hawaiian/Indigenous researcher, as “the idea of Need, or how best to be of service to our community” (p. 249).

### *My role as a learner*

As a researcher working with Cree and Cree-Métis women, Elders, and communities, I took on two distinct but inter-related roles. One was my role as a learner. Not only was I the learner in terms of the research project and its objectives, but also in relation to the Elders. In this instance, I was there to learn from them and to gain further understanding of the cultural teachings and knowledge that were important regarding Cree and Cree-Métis women’s sexual health and overall health. During a one-day gathering with the women Elders, we spoke together about what I was ready to learn or what would be appropriate for the Elders to share at this time. Although the content of my learning was never explicitly stated, the Elders talked about the pace of my learning as important. For example, Isabel Auger stated,

> *Slow down on your spirit. You are anxious to know a lot of things. ...you need to go back and relax.*

Additionally, we discussed the need to be clear regarding my intentions and what kind of knowledge that I was asking them to share. It was important to the Elders that I understand whatever information they would be willing to share and also that I was aware that accepting this knowledge came with personal responsibilities. In speaking to these issues, Isabel Auger talked about her own responsibilities towards the teachings and knowledge that she had learnt. She likened her responsibility of the teachings and knowledge to the commitment that she held to her children. Isabel stated,

> *You must know – to be equal to know the road to help other people. You must have the sacred stem in the bowl [tobacco] to be able to help others. To me, I hold it to my chest and just like my children when I nursed my oldest girl and my boy. No, I can't break that promise. I kept them here [points to heart]. That rule I will not break. I belong to it.*

Isabel also talked about my responsibilities in the sharing of cultural teachings and knowledge. She referred to the need for me to remain clear and focused on my intentions when she stated,

> *There's a very narrow path right now. Let's keep it that way. It's not a wide path so we can walk two by two. Let's walk on our narrow path because a narrow path leads to our Creator. ... Once you walk down, you're walking in your Grandmother's path now.*

The importance of relationship building with Elders based in trust cannot be overstated. The ways in which these women Elders proceeded to discuss these issues reflect the importance of building trusting relationships in working with Elders and in sharing cultural knowledge and teachings. Through going to visit with the Elders and by bringing them together while remaining open regarding my intentions, we were able to establish the trust that was needed to proceed further. In the end, the Elders and I decided upon what kinds of teaching and knowledge would be shared during the gathering and agreed that we could and would proceed. This was reflected in the following statements by Isabel Auger:

> *I know where you are coming from. I know what you are going to go through.... [Together we can] put the package for her in the proper way. I think you have picked the right women to do that. But you were directed to us.*

### *My role as a facilitator*

My other distinct role, during the research and in working with the women Elders, was as a facilitator. This role would evolve for several different reasons and in several different ways. First, a goal of the research was to create the safe environment that would be required in order to work with the Elders in relation to the sharing of cultural teachings and knowledge. This was done largely through enabling the principles of the research – respect, reciprocity, and relationship building – to guide the methods and activities of the research. These methods and activities needed to be embedded within the practices and protocols of the people who were involved. In particular, the offering of tobacco to the Elders was instrumental in creating a safe environment. The Elders talked about the significance of tobacco each time that I visited them and several times during the gathering. For example, Alice Reid talked about offering tobacco to an Elder in a respectful way that would enable the Elder to see the offering as a choice. As well, I cited Isabel Auger earlier when she talked about tobacco in relation to respect and reciprocity. Rita Auger also talked about the importance of tobacco in relation to showing respect and talking about the traditional teachings and knowledge of Indian peoples when she stated,

> *But the tobacco here that you give us, this is the transmitter, the translator. That's the head. Always offer tobacco to someone if you want to [learn]. This is the*

> *respect I give people first. ...without it, we can't really speak about ourselves as Indian people.*

By following the practices and protocols of the Cree and Cree-Métis peoples involved in the research, respect was shown for 1) the Elders and their knowledge, 2) for the processes necessary to share cultural teachings and knowledge, and 3) for the sources of the teachings and knowledge – the Elders, the ancestors, and ultimately the Creator. Additionally, the 'fundamental law of reciprocity', as an expression of Cree and Cree-Métis peoples and their epistemologies, was then given meaning. Through the offering of tobacco, reciprocity occurred 1) between the sources of cultural teachings and knowledge and the beneficiaries of the cultural teachings and knowledge, such as between the Creator and the Aboriginal peoples, 2) between the receiver and teachers of cultural knowledge, and 3) within the relationships of the people that were engaged in these processes. Through the establishment of these relationships based on the principles of the research, sharing cultural teachings and knowledge significant for Cree and Cree-Métis women's health and wellness then became possible.

The second way in which my role as a facilitator transpired was through creating an environment in which the Elders could proceed according to their own customs and practices. This was again achieved through following protocol and enabling the Elders to participate in their own dialogue with one another. In other words, creating an environment that was comfortable enough and appropriate for the Elders to converse with one another. By having Elders together who knew and trusted each other, they would engage in their own necessary processes to address what I was asking of them in relation to Cree and Cree-Métis women's health and wellness. Alice Reid played an important role in this process through sharing many stories about her family and community and through inviting the other women Elders to share their stories. I would later come to understand the significance of proceeding in this manner.

In summary, these two roles that I assumed in working with the women Elders were, in fact, also the same roles that I assumed in working with the women. I engaged with the women who participated in this project in order to learn about their cervical cancer experiences. I also learned, as described later in chapter six, that these women would talk about these illnesses as only one experience affecting their health and wellness. This was due, in part, to the questions that were asked but also because the principles of the research enabled the focus of the research to be on the mutuality of our relationships and not solely on my individual learning. In this way, the processes of my research contributed to and, in significant ways, facilitated the transformation of the women in their own learning as well. Weber-Pillwax (2003) refers to this kind of personal transformation of Indigenous individuals when she talks about "synchronic analyses…as connected but distinct processes" in which individuals look for and make meaning out the events of their lives (p. 195). The facilitation function that I assumed during the work with the Elders would also become important in that it contributed to the ways in which the Elders engaged in their own very important processes (as discussed within chapter seven).

### *Aboriginal spirituality*

The final part of this discussion talks about Aboriginal spirituality as a fundamental underpinning of many Aboriginal cultures and traditional beliefs and the significance of this for my research. I have heard Elders say that Aboriginal spirituality is not a religion, but a way of life. This is supported by the fact that Aboriginal peoples are conscious of their relationships to the world around them and how they are part of something bigger than themselves[16] (Ermine, 1995; Goudreau, 2006; Weber-Pillwax, 2003; Wilson, 2001). Weber-Pillwax (2003) states, "Indigenous peoples live out their lives in complete awareness that their lifeworlds are embedded within a larger and more powerful social reality" (p. 8). Further, Hampton (1995) states, that "[T]he first standard of Indian education is spirituality. At its centre is respect for the spiritual relationships that exist between all things" (p. 19). This is why events or gatherings with Aboriginal peoples usually begin with prayers to the Creator that acknowledge, among other things, our relations to the world around us. The one-day session with the Elders proceeded in this manner and this beginning or contextualization for the event was integral to the creation of a safe and appropriate environment from which the Elders could share and I could learn about cultural teachings and knowledge.

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[16] Personal Communications – Elders John Crier & Jimmie O'Chiese. March, 2007. A Mental Health Gathering for Communities Interested in Mental Health Research: A Joint Collaboration between the Alberta ACADRE Network, CURA Healing Through Language and Culture, and Aboriginal communities.

As well, Hampton (1995) states that as Aboriginal peoples, "[O]ur traditions define and preserve us" (p. 29). Participating in the spiritual practices or traditions of Cree and Cree-Métis peoples during the Elder's gathering worked to bring us together through the expressions of ourselves as Cree and Cree-Métis peoples. As stated earlier, the Elder's gathering did begin in prayer. This enabled us to acknowledge our relations, which included our ancestors. Ancestors of the Cree and Cree-Métis peoples are as Weber-Pillwax (2003) states, "the origins or starting point of the knowledge that is available to us" (p. 11). Acknowledging these significant relationships and connections to our ancestors would then work to 'preserve us' as Cree and Cree-Métis people.

Further, Anderson (2000) states that ceremonial space enables Aboriginal women to move away from a 'negative Aboriginal female identity' (p. 111). This 'movement' of entering ceremonial space may be further understood through the way in which Elder John Crier[17], during a discussion on Aboriginal peoples and mental health, talked about ceremony and the reasons that ceremonies were and remain integral in the lives of Aboriginal peoples. He stated, "The reasons these ceremonies were done is [that] they were done in a way that our soul and our spirit was able to function – it expressed a release, [such as] fear, joy, or sadness". Further John stated, "[E]verything points back to our ancient teachings – they speak of how we function. We are more than just flesh and bones. There is something bigger than us. Ceremony allowed us to be in that ritual space…where the soul is in charge of the body for healing". Practices that enable the individual and collective expression of Aboriginal spirituality, such as participation in ceremony and prayer, helped to move the research and its processes away from the negative images of Aboriginal women. Unfortunately, these images are, more often than not, found also embedded within health research about Aboriginal women and are as Hampton (1995) makes reference to: analogous to "measuring the life of the seeds by counting the dead plants" (p. 35). Through participating in ceremonies, the participants of the whole research, including myself as the researcher, the women, and the Elders worked in ways that were potentially liberating for Cree and Cree-Métis women in relation to their sexual health and wellness.

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[17] Personal Communication – Elder John Crier. March, 2007. Edmonton, AB.

### *Theoretical Perspectives & Data Analyses*

Working to analyse the data of this research from perspectives that would enable appropriate and valid interpretations required again an approach that was Indigenous in *nature*. This meant that the 'lens' through which valid interpretations could be made and appropriate conclusions could be drawn needed to reflect the lifeworld of Cree and Cree-Métis women while considering the worldviews of the peoples and communities involved in the project. As identified earlier, the work of Martin (2002), Meyer (2003), and Weber-Pillwax (1999/2003) formed the theoretical foundations for the basis of such an approach and were instrumental in the development of this research framework. The core features of Indigenous research identified by Martin (2002) and the issues specific to research with Indigenous peoples outlined by Weber-Pillwax (1999/2003) were cited as being consistent with the specific criterion of the research approach. As well, I cited the work of Smith (1999) in talking about this work as utilizing a blend of western research methods and Indigenous practices. Further, I referred to the work of Weber-Pillwax (2003) in relation to following the steps that I needed to follow in order to conduct the research and in allowing the methodology to arise out of the needs of the peoples and communities involved in the project. The natural progression of this research from within an Indigenous framework was built upon these premises. The theoretical foundations for data analyses from Indigenous perspectives in this study largely drew upon and were based in the work of Hawaiian/Indigenous researcher and scholar Meyer (2003). The work of van Manen (1991/1997) on interpretation of data using an hermeneutics approach also proved to be useful in its application as a tool for interpreting the stories and perspectives of the women who engaged in the research processes of this work.

### *From van Manen to Indigenous hermeneutical perspectives*

In analyzing the stories of the Cree and Cree-Métis women, I found myself questioning what gave me the right as a health researcher to give voice to these experiences. Being a woman of Cree-Métis descent myself seemed to be insufficient justification to drawing meaning from the experiences of these women who had entrusted me with their stories. However, in searching for the uniqueness of Cree and Cree-Métis women's lived cervical cancer experiences, what I found was an inter-relationship between what these women had experienced and what I believe most Aboriginal women (including myself) experience in their daily living. That is the pedagogic situation of being an Aboriginal woman in today's world.

Van Manen (1997) asserts that pedagogic situations are unique and states that theory of the unique is needed to strengthen "the intimacy of the relationship between research and life…." (p. 155). Meyer (2003) talks about Indigenous interpretation as possessing the "potential to liberate us" through reflecting the wholeness we believe in as emanating from ancient epistemological truths (p. 250). Through studying the uniqueness of Cree and Cree-Métis women's cervical cancer experiences, theory should then have emerged that is specific or 'suitable' to working with Aboriginal (or Indigenous) women with comparable experiences. Such theory, for example, may be seen as emerging in chapter five in relation to the fear and mistrust that Cree and Cree-Métis women reported with regards to cervical cancer experiences.

The analyses in this research are built upon the theoretical assumptions of Meyer's (2003) description of Hawaiian hermeneutics, but are essentially Cree and Cree-Métis/Indigenous women's perspectives exactly because the peoples directly engaged in the work are Cree and Cree-Métis/Indigenous women, including me. This research finds its further significance in both the 'uniqueness' and the similarities of the overall health and daily lives of these women who have experienced cervical cancer. Hermeneutic interpretation, based in the realities of Northern Cree and Cree-Métis lived experience, reflects the unique ways in which these women view their health and illness. For example, from the stories and voices of these women emerged the clear inter-relationships between body, mind, and spirit as the 'meaning dimensions' that gave this data its distinct qualities. Further, these similarities and/or unique features of the Cree and Cree-Métis women who participated in this research are presented in this document as reflecting this wholeness.

### *Processes of data analyses and the women's stories*

> *Making something of a text or of a lived experience by interpreting its meaning is more accurately a process of insightful invention, discovery or disclosure – grasping or formulating a thematic understanding is not a rule bound process but a free act of 'seeing' meaning. Ultimately the concept of theme is rather irrelevant and considered simply as a means to get at a notion we are addressing. Theme gives control and order to our research and writing. (van Manen, 1997, p. 79)*

Thematic analysis was used to locate the 'shared' or common experiences found within the women's stories. Van Manen (1997) describes thematic analysis as the "process of recovering" themes or commonalities that are "embodied and dramatized in the evolving meanings and imagery of the work" (van Manen, 1997, p. 78). He also states that there are "phenomenological" or interpretive qualities to the experience of articulating a theme (p. 88). The four qualities van Manen (1997) delineates are as follows:

1. Theme is the needfulness or desire to make sense.
2. Theme is the sense we are able to make of something.

3. Theme is the openness to something. (the promise of a notion embedded in lived experience)
4. Theme is the process of insightful invention, discovery, and disclosure.

In hermeneutic interpretation, van Manen (1997) says that themes are ways to structure the data and are not lofty things. The importance of naming themes is then to show how they are lived out in life through life descriptions. Upon close examination of the women's stories in the transcripts, initially drawing on the idea of Van Manen's hermeneutic interpretation, common themes began to emerge. In this way, nuances in everyday life that are often covered over with ordinariness, come into view. An example of this may be those parts of the women's stories where they talked about what it is like to consistently experience pain and fear during cervical cancer treatments and procedures and then to have to return for repeated pelvic examinations.

Further and in my work to locate the themes in the women's stories, through reading the text and listening to the interviews, I found that particular statements and phrases, taken together, often revealed an overall meaning of that part of their experience. In this way, the lived experiences of these women, as shared, became more than "conceptual abstractions"; they could then be understood as "shared structures" of cervical cancer experience for Cree and Cree-Métis women (van Manen, 1997, p. 79). This approach, or what van Manen (1997) calls "the selective or highlighting approach", was helpful in making sense of the commonalities or 'shared' lived experiences reflected in the women's stories of cervical cancer (p. 93). For example, all of the women spoke about their frustrations in dealing with male physicians, nurses, and hospitals and clinics. Taken alone, each of these statements can mean that there are important issues and challenges for Cree and Cree-Métis women related to each of these facets of care; however, when these phrases are taken together, they seem to point to or identify a disconnection or incompatibility between the health care/delivery system's approaches to treatment and care and the needs of those Aboriginal women. The following excerpt from the story of Marla illustrates the apparent lack of empathy she feels is being shown on the part of the physician, and the statement reinforces how she associates visiting the physician and going through the *necessary* treatment with fear and pain:

> *I just don't feel comfortable around doctors anymore because when they first found it, I'd be tensed up on the table and I'd be like [shrugging] cause I just hated it and it hurt. They had to do little biopsies back then and it hurt. You feel like someone s pulling on your insides and they'd be asking, are you okay? Or this won't hurt very much. What the hell do you know? Have you ever been through it? It felt like they were all over inside you. But there was never any other pain. They say it's worse if you don't feel pain than it would be if you do. So I felt no pain. The only time I did was each time I had to go through that procedure.*

Van Manen (1997) states, "that in determining the universal or essential quality of a theme our concern is to discover aspects or qualities that make a phenomena what it is and without which the phenomena could not be what it is" and further, "that one theme always implicates the meaning dimensions of another theme" (p. 107/p. 168). This is similar to what I found in the themes that emerged from these women's stories in relation to cervical cancer experiences. All of the women talked about their experiences with cervical cancer as possessing particular 'essential' qualities – such as pain and fear. In some ways, fear, related to diagnosis and treatments, seemed to have led to increased pain in the experiences of the women. In this way, then, pain and fear were described or found to be inter-related and inter-dependent upon each other. In the first section of chapter five, an analysis of the data is presented utilizing a systematic approach regarding commonalities or themes. Further, the themes are also discussed in terms of how they are shown to build upon current research in this area of concern with other Aboriginal women.

This initial analysis of the data from the stories of the women identified several themes in relation to their experiences with cervical cancer. However, further study of this data and the data that was complied with the women Elders revealed that there was much more to be learned from their health and illness experiences as Cree and Cree-

Métis women. While collecting the data and in working with the women who shared their stories, I began to realise that cervical cancer illness, as an experience, was not the focus of their discussions. In order for them to clearly and fully tell me their stories, a context was needed from within a cultural perspective that would be more appropriate to discuss these issues. That context, I knew from the onset, was from within the context of women's overall health. It then made sense with regards to the relationships that we were building that our discussions would proceed within these contexts in order to gain a comprehensive understanding of the 3 guiding questions that led the interviews: How do Cree and Cree-Métis women describe their health and illness? How do Cree and Cree-Métis women perce[illegible] their diagnosis of cancer? How do Cree and Cree-Métis women integrate their illness into their worldview? Further, a detailed question list was devised, as found in Appendix G, to engage the women in discussions in relation to these three issues.

The challenge I now faced in analysing the data from the women's stories and the data from the Elders was related to Meyer's (2003) work on hermeneutics as the interpretation that arises out of your orientation and way of being in the world (p. 250). In trying to use the available strategies or methods of western research, I found that none of them quite met my needs or enabled an interpretation of the data from within appropriate contexts. Appropriate contexts would support the presentation of the data as 'valid' and 'reliable' sources of interpretation in relation to what I was seeing as emerging in the research. In short, I faced an issue that Meyer (2003) had identified as arising out of the *spiritual facet of epistemology* for Indigenous peoples: "How to discuss cultural realities that are out of context with those who struggle with their own fractured cosmology" (p. 254). The development of unique strategies or methods in order to analyse the research data included the further development of the concept of Indigenous Hermeneutic Interpretation and the unique strategy that was developed in order to access the Cree data that I had collected in working with the Elder women.

### *Indigenous methods of data analyses*

Meyer (2003) calls her theorizing in relation to hermeneutics "Hawaiian Hermeneutics" because she is Hawaiian and she states that what she has learnt originates with her ancestors and from many scholars around the globe (p. 250). Similarly, we are both from Indigenous peoples and believe that "[A]ll ideas come from ancient systems" which have helped us to learn how to think (p. 250). For example, Weber-Pillwax (2003) in her work on identity formation with reference to Northern Alberta Cree and Cree-Métis peoples, talks in detail about the starting point of knowledge that is available to us as Cree and Cree-Métis peoples as originating with our ancestors; in fact, this is a point that she alludes to several times throughout her work. Although I possess little or no knowledge of Hawaiian culture and knowledge systems, I feel that we as Indigenous scholars, researchers, and peoples are at a point in our academic discourse where several assumptions can be made with regards to the commonalities that exist in relation to the historical, political, social, and cultural worldviews that shape and affect our lives and experiences as Indigenous peoples. Beyond this point then, I refer to the theorizing of Meyer (2003) and my own thinking in relation to hermeneutics as 'Indigenous Hermeneutics'.

Meyer (2003) entitles her work, *Hawaiian Hermeneutics and the Triangulation of Meaning: Gross, Subtle, Causal*. She talks about *Gross* knowing as "a 'seeing'…of what is present in the moment of experience" (p. 251). Using words such as objective, physical, place, and body, Meyer (2003) calls this the lowest form of knowing in which, for Indigenous peoples, there will already exist discernable differences in comparison to non-Indigenous peoples. Indigenous peoples, by virtue of how they experience the world around them possess an external knowing or "a seeing" that differs because it includes "a rationality that is born out of sustained consciousness" or what might be alluded to as blood memory and "relationality" with regards to *place* (p. 250). Not simply where you are physically in the world, but the idea that all things are seen in relation to each other. As an Aboriginal person, I have heard many Elders say that *we see* the world around us as encompassing much more than what physically appears before us. Hence, the rationale for many of the ceremonies that enable us to transcend from the physical plane of existence and connect to the spiritual part of ourselves and our environment.

From here, Meyer (2003) talks about this external reality as an experience that includes symbolic, personal, and interior knowing. For Indigenous peoples, she states, this *Subtle* knowing reminds us that how we view the world around us is a matter of what we value, where we live, what we think about ourselves, and surviving our differences as Indigenous peoples in relation to the mainstream world or western thinking. What emerged from the data of the women in relation to their health and illness experiences was the internal knowing that helps to form their sense of themselves as Cree and Cree-Métis women. This encompassed all those things that Meyer (2003) talks about as being a matter of what we value. If I had not possessed a similar sense of myself, as a Cree-Métis/Indigenous individual and woman, I may have failed to recognise these in the stories and experiences of the women.

Finally, Meyer (2003) refers to the *Causal* where knowledge becomes more of an event or “a stirring”, which includes what she describes as “the deep animating principle found in matter” or the “spiritual facet of epistemology” for Indigenous peoples (p. 254). This ‘spiritual facet of our epistemology’ as Cree and Cree-Métis peoples was alluded to during all the conversations that I held with the women Elders. Just two examples were the Elders’ discussions around tobacco and prayer and the need to address healing in relation to the spiritual part of ourselves as Cree and Cree-Métis peoples.

In closing this first part of the discussion on the development of Indigenous research methods, Meyer (2003) states, “it is precisely here, at the center of what experience means where we must be clear” (p. 252). Through clear descriptions of the lived experiences of Cree and Cree-Métis women of Northern Alberta, and by articulating the significance of the meanings of these experiences, it then became possible to talk about these from appropriate perspectives or the perspectives of Cree and Cree-Métis peoples. In this way, what I would learn from this research in trying to reflect the wisdom of these Cree and Cree-Métis women is that the *collective Self may only come to bear* at what Meyer (2003) calls “all points of this triangulation” or where our voices reflect the wholeness that we believe in (p. 250).

The second method of data analysis developed during this research was in response to the traditional teachings and knowledge that were contained within the stories of the Elder women. Traditional or cultural knowledge and teachings are rarely conveyed through the asking and answering of direct or specific questions and answers (Cajete, 2000). Also critical to the writing of accurate descriptions of cultural teachings and knowledge were the contexts of the data and their underlying meanings. It would have been considered disrespectful and/or unethical to view the cultural knowledge and teachings of the women Elders from within a foreign worldview; therefore, placing the shared knowledge from the Cree and Cree-Métis women within western constructs of analysis or providing an explication of this knowledge from a western perspective was avoided. Close consultation and direct knowledge input from the women Elders and the Aboriginal members of my research committee assisted in the interpretations of Cree and Cree-Métis knowledge and its meanings.

The work of accessing the data involved two layers of translations for some sections of the collection. For example, dialogue with the women Elders often occurred in the Cree language, which is not my first language and required initial translations into English. Accessing this data also raised several issues and challenges. First, all of the women I interviewed who had experienced cervical cancer spoke in English. However, I had encouraged the women Elders to establish their own format for engaging in their own dialogue in relation to the research. This meant that they would speak in their Native language, Cree. As well, a goal of the research was to obtain cultural knowledge and teachings in relation to Cree and Cree-Métis women's sexual health and overall health. As this knowledge is always embedded in the original languages of the people, the stories and cultural teachings in this project were more fully and appropriately understood only within the context of the Cree language. Challenges in relation to accessing the Cree data included financial costs, feasibility, and personal trauma associated with a sense of loss around language and culture. Some of the challenges related to the financial costs of translating and transcribing the Cree data were overcome through the financial support of the Alberta ACADRE Network and a SSHRC - CURA project, entitled Healing Through

Language and Culture. However, it should be noted that student funding to support these kinds of costs is extremely limited[18].

Further, acknowledging the expertise of the community and valuing their knowledge was dependent on enabling the expression and meanings of that knowledge in the most appropriate form or language (Ermine *et al.*, 2004). However, as an English language speaker who does not understand the deeper nuances of the Cree language, it was unclear to me how the translations of the Cree data in this study would affect the final outcomes of the research. For example, would a literal translation work the best or would a form of translation that includes identification and consideration of the Cree concepts within the data work the best?

In order to address my concerns and the similar concerns of other Aboriginal students, a Cree language data analysis session was held at the university. While some of the students and faculty in attendance acted as translators and interpreters during the session, all of the people in attendance played a role in analysing the Cree concepts and teachings that emerged from some of the data. Essentially, these colleagues provided a valuable source of peer review and member checking for parts of the Cree data in this research. Although a similar type of data analysis is referred to by van Manen (1997) as a form of "collaborative analysis", the distinct context and purposes of this creative method were devised for our Cree purposes and were realised in the triangulation of data that requires compensation for our inability to understand the language (p. 100). We were working across two languages and therefore, two knowledge systems and two distinct sets of meanings.

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[18] As Aboriginal researchers, we suggest that the loss of languages for Aboriginal students is tied to the historical experiences of all Aboriginal peoples and is an issue that needs to be addressed in relation to Aboriginal students doing health research in their own communities with their own peoples – Aboriginal Researchers Gathering, Bourque-Bearskin, Memnook, Sinclair, Sockbeson, Steinhauer, and Weber-Pillwax, October, 2007.

*Methodology Conclusions*

Many of the participants, such as the Elders and community members involved in this work, were individuals with whom I had been connected for many years in a professional or personal capacity. For the most part, Elders and community members knew each other and of each other's work and professional involvements. This supported a commitment to work together as many of the relationships of trust and respect were already in place. Those relationships that were new were bridged by the relationships already established. For example, meetings with women's groups in Northern Alberta Cree and Cree-Métis communities enabled me to participate in community events with professional colleagues. This helped to support introductions to possible research participants and the building of these new relationships. Further, this is the proper Cree way to begin such a process, especially one that holds a strong potential for stigmatization and the promotion of further pathologizing views of Aboriginal women in relation to their sexual health. All process decisions were made in consultation with the participants of the research. A one-day session with the Elders and a professional colleague and Northern Alberta Cree community member was held once all the interviews with the Cree and Cree-Métis women were conducted.

As would be appropriate to a qualitative research project, a strategy for the triangulation of data was imposed on this study. Triangulation of data was important to this project for at least two specific reasons. First, it may be viewed by western science as an alternative to the validation of findings that are often considered to be more elusive in qualitative research approaches (Denzin, 2002; Denzin & Lincoln, 2000; Van Manen; 1997). From a western perspective, triangulation in this study was provided through the multiple methods used to collect the data, the use of reflective journal writing, and through member checking with professional colleagues, community members, Elders, and committee members as ways to ensure that the analysis and interpretations of the data accurately reflected the words and voices of the participants. The second and equally significant point of triangulation was the obvious relationship between repetition and truth, a concept that is common in the epistemological premises of Northern Alberta Cree and Cree-Métis peoples and many other Aboriginal peoples. Written evidence of this is found in the research of Goudreau (2006) where she states, "[T]oday, Aboriginal women such as the ones in this study are finding their voices and speaking their truths. Their voices are important if we are to overcome the violence, oppression, racism, and poor health conditions that many of them face" (p. 107). The First Nations, Métis, Inuit Steering Committee and Working Committee (2004) developed *A Teacher Preparation Resource Package for Faculties of Education and Alberta Learning* in relation to Aboriginal peoples. There in, they state the following:

> *"It is not my voice, it is not 'I,' it is one, and only one. And does not become anything unless it is repeated elsewhere. Repetition is a facet of Indigenous knowledge that is minimized. If one says something, and someone else repeats what is said, and you hear it repeated again, then what is heard holds validity in the context within which it was spoken. To hear something from one source is to hear it from one source alone. When many voices speak the same words, then what is heard has value and may be held to hold truth. This is so for the creation stories. I have heard the creation stories of several nations and read those of many nations, and there are common themes that are shared. Then, the stories may be considered as valid, as 'evidence,' as fact and therefore as truth" (First Nations, Métis, Inuit Steering Committee and Working Committee, 2004, p. 1-63).*

This research project with Northern Alberta Cree and Cree-Métis women enabled their voices to be heard and their viewpoints to be expressed through the sharing of their own stories. Precisely because the purpose of qualitative research is to reveal the identities and stories of the people, reflecting the viewpoints of the participants in this research through commonly accepted and culturally appropriate methods, such as story telling also represented a form of knowledge transfer for Cree and Cree-Métis women and communities (Smith, 1999). Reintegrating or reincorporating the voices and stories of the Cree and Cree-Métis women into the information that was given back to the participants and communities honoured storytelling as a Northern Alberta Cree and Cree-

Métis way to share personal and collective learning and, at the same time, honour the experiences of Cree and Cree-Métis women.

This collaboration between Northern Alberta Cree and Cree-Métis women, Elders, communities, and the researcher was the first important step to renewing current understandings of the health community and its researchers of the influences and impacts of culture on the sexual and overall health of Cree and Cree-Métis women. Allowing for the naming of Elders and knowledge keepers was a vital component that enabled the project to recognize the individuals with whom the knowledge originated and was also a way to respect the teachers of the knowledge. The decision to name individual Elders was made at each juncture in which their words appear within this document. Finally, as the researcher, I openly accepted the responsibilities that were inherent to the outcomes of this research process. This included a personal responsibility to the participants and their communities, an academic responsibility towards the university and my professional colleagues, and a responsibility to the data through ensuring its honest reflection of what was learned. Moreover, this research also accepted those responsibilities that are reflective of ethical principles and practices in research with Indigenous peoples as demonstrated through activities such as returning the data to participants and Elders. All names and associated communities of the Cree and Cree-Métis women who shared their stories in relation to cervical cancer have been replaced with pseudonyms in order to protect participant confidentiality and anonymity.

### *Chapter Summary*

In summary, this chapter identified the methodological framework developed for this research as Indigenous. I began by providing the reader with a description of the position from which I speak as a Cree-Métis individual. I then talked about the philosophical underpinnings of the research framework, such as the five core features of Indigenous research identified by Martin (2002) and the important issues to be considered in relation to research with Indigenous peoples as outlined by Weber-Pillwax (1999/2001/2003). These were discussed in relation to the criterion of the research that was necessary in order to work in a culturally appropriate and safe manner with Cree and Cree-Métis women, female Elders, and communities in the area of female sexual health. I then discussed thematic elements in my learning that emerged in relation to learning from within Indigenous contexts. These were suggested as emerging to form a cyclical pattern that enabled the research and its processes to build upon one another in a spiral fashion. In addition, the recurring themes of the research itself were shown to transpire in a similar manner, which ultimately led to a search for appropriate methods of data analyses outside the available sources provided by western research. This, in turn, helped to create two new methods for data analyses in this research – one based in Indigenous Hermeneutics and one developed for accessing data in the Cree language. In conclusion, I presented the strategies or methods of triangulation used during this project and addressed the concepts of reliability from Indigenous perspectives.

# CHAPTER FOUR: PATHWAYS & PROCESSES OF THE RESEARCH

In this chapter, I outline the progression of the study and the research processes as they unfolded in working with Cree and Cree-Métis women, women Elders, and communities. First, I talk about the participants and describe their roles during the research. Next, I describe the research steps and events that occurred. In the final section of this chapter, I discuss the methodological challenges that arose in relation to carrying out the research in ways that were sensitive to the needs of these women and to the requirements of the cultural protocols for entering into their communities.

Although the chapter is set out in a step-by-step format that enables the reader a fuller comprehension of how the study took place, each part of the process essential to working with the women and Elders evolved in a cyclical pattern. This pattern again showed that activities and learning in this research occurred and built upon one another in a spiral fashion, ever broadening. Further, the steps that were taken prior to conducting the research, those during the study, and those continuing through to today symbolize and differentiate a framework that maintains respect, relation, reciprocity, and honour for guiding health research with Cree and Cree-Métis women, Elders, and communities.

*The Participants*

All of the participants in this research self-identified as Cree-Métis or First Nations Cree from across Northern Alberta. The five women who shared their stories and experiences with cervical cancer were all between the ages of 32 and 57. All were mothers of school aged or grown children and most were grandmothers. In addition, four female Cree and Cree-Métis Elders from across Northern Alberta were involved for the duration of the project.

Interviews with the five women who had experienced cervical cancer took place on a date and time that was convenient for them in their own homes. Approximately 2.5-3 hours were needed to discuss and obtain written consent, complete all the questions, and answer any questions that the participants asked. The questions were grouped into four sections. The first set of questions dealt with age, gender, community membership, and level of education. Although I was uncertain at the time of the interviews as to the usefulness of obtaining the participant education levels, it quickly became apparent that this information might be helpful in terms of identifying what types and how much knowledge the women seemed to have of cancer prior to their own diagnoses and what level future education might need to be in order to target and address the concerns of other women from similar backgrounds. Participant Madelaine spoke about the question regarding education when she stated, “I can understand the education question though because if you have an open mind and are willing to examine a lot of the issues that are going to be discussed in this, it probably gives me more of a freedom. And I want to learn as well.”

The second set of questions asked each participant what it meant to be healthy and sick and what kinds of activities she participated in while healthy and while sick. The third set of questions sought information specific to cervical cancer experience and the woman’s own experience, including the diagnoses and treatments that were received. Finally, the women were asked about how they felt that their lives had changed. This final set of questions was largely reflected in what the women had already said throughout the interviews.

At the beginning of the study I planned to interview 6-8 participants but soon found that some of the women I had been meeting with were having mixed feelings about their involvement in the research. The women who stayed involved for the duration of the study reported that their decisions to participate were due to a strong desire to prevent other women from getting the disease, the view that further education is needed to prevent other women from contracting the disease, and a belief that sharing their experiences would have a healing effect or provide a healing power that could be obtained through sharing the experience. One participant stated that *in order to heal, she needed to give the story away.* These reasons reinforce the Indigenous processes of the research and its learning from within Indigenous contexts which find that, "[R]esearch for us is not simply about asking 'burning questions' we want resolved, but rather, we are answering a call to be of use" (Meyer, 2003, p. 249).

In addition to the time spent with these women and their interviews, I spent a great deal of time on several different occasions with the Elders. Informal visits and time spent with Elders prior to the interviews with the women helped me to identify key areas of health and wellness that were addressed during the women's interviews. During the time spent with the women Elders, I was seeking their perspectives in identifying and understanding those philosophies, teachings, norms, traditions, and ceremonies that envelop Cree and Cree-Métis female sexual health. This included elements and/or constructs significant to Northern Alberta Cree and Cree-Métis sexual health (ontological considerations) and how these operate through Cree and Cree-Métis ways of knowing (epistemological underpinnings) in relation to female sexual and overall health. As well, ill sexual health and what the Elders identified as affecting or causing ill health was also discussed in order to provide contexts for the women's discussions on cervical cancer.

I engaged in at least two informal visits with each Elder involved in this project, which usually lasted between two and four hours. These visits took place over a period of three months. Participant interviews with the Cree and Cree-Métis women lasted approximately 2.5-to-3 hours and in addition, one or two visits with the participants prior to conducting the interviews also occurred in order to allow for the development of a trusting relationship. Due to the time required to transcribe interviews and to develop narratives, the goal was to return the narratives to participants within a two-month time span. Carrying out this portion of the research took approximately six months. An additional six months were needed in order to complete a final one-day session that was held with all of the Elders and to then translate and transcribe the Cree texts.

Analysis of the women's experiences included the development of narratives from the transcribed interviews. This was then returned to participants in order to identify any concerns or deviations within the text to what the participant had said or had meant to say. Thematic and text analysis were done and only those words and stories of the women that have direct meaning and purpose to the analysis were revealed in order to avoid pathologizing the lived experiences of these women as much as possible. As well, I kept a personal diary and entered field notes related to experiences and discussions throughout the development and implementation of the research. Included in the field notes were thoughts, directions, questions, impressions, and ideas related to the interviews and discussions that arose during the research. These notes were used to identify concerns, provide contexts for discussions that occurred prior to and after the actual interviews and to ascertain the valid and reliable points of the gathered information.

Analysis was ongoing as the interviews were being transcribed and the narratives were being developed. Analysis of the participant interviews provided themes that were then discussed with the Elder group during informal visits and the Elder gathering. The Elders, as knowledge keepers, acted as co-researchers in this sense as their discussions were used to validate the findings and contribute further insight into how cultural norms and traditions supported the sexual health and overall health of the Cree and Cree-Métis women. Narratives of the women's interviews provided themes, as well as, unanswered and new questions that could then be discussed with the women Elders. At no time, did the Elders view the transcripts or the narratives that were developed from the individual interviews with the women.

The final session with the Elder women contributed to and built upon my analyses of data drawn from the women's stories and experiences. This process ensured findings that built upon the perspectives of Cree and Cree-Métis Elders, as well as, those of the women's themselves in relation to Northern Alberta Cree and Cree-Métis women's sexual health and overall health. Factors that affect Aboriginal women's sexual health and wellness were identified and shown to be present in the cervical cancer experiences of these Cree and Cree-Métis women. This may contribute to better understandings of the health service and education of Aboriginal women in relation to their sexual health and should alert the health care community and policy-makers to the significance of cultural knowledge and teachings for the health and wellness of Aboriginal women and their communities.

Previously, I have talked about the research as taking place in three separate, but interrelated phases and made reference to the activities and processes of this research with Northern Alberta Cree and Cree-Métis women, Elders, and communities as evolving in a cyclical fashion. In the rest of this chapter, the steps of the research are described in a linear format, but the work with the Elders and the women will also be shown to be building upon one another and not, therefore, having had occurred in isolation of one another. I begin by describing my roles in the research and the roles of the Cree and Cree-Métis women, Elders, and communities in the development, implementation, and analyses of the research study.

### *Roles of the researcher and research participants*

As noted earlier, I cannot overstate the importance of relationship building in this research. The investment of time and energy by the researcher and the participants into relationship building continues into today and will most assuredly support further collaborative work in this field of study, well beyond the duration of this project. Principles of trust and relationship building are reflected in the roles of the research participants – myself as the researcher, the women who shared their stories, and the Elders who shared their cultural knowledge and teachings.

I stated earlier that my main role in the research was that of a learner and, it was only late in the research process, that I recognized myself in the role of accomplished facilitator for the whole research process. Without the trust that was inherent in the network of relationships between myself and the women and myself and the women Elders, it is less likely that I would have recognized in myself those skills and that capacity to fulfill those functional aspects and specialized skills required for the facilitation of such a process. From another aspect, as an Aboriginal nurse, I was also called upon to play a role in sharing my professional knowledge with the women, the Elders, and their respective communities.

At the onset of the project, I utilized different strategies to meet with potential participants or Aboriginal women who had experienced cervical cancer. On two separate occasions, I traveled to Northern Alberta First Nations and Métis communities and presented my proposed project to health service providers and some of the women who lived there. On one such visit, I hosted a seminar at the health centre. Attended by health centre staff, this seminar provided opportunities to teach and answer questions regarding the potential significance of this issue for First Nations and Métis women. As many of these women were the service providers who work directly with the people of the community, this had some distinct advantages for my project. For example, the health centre staff now knew that my presence in the community held a purpose and they could easily explain this to community members who might be interested. As well, these service providers were, more often than not, community members themselves and entrusted by the community that they served; therefore, gaining their trust and speaking to any concerns that they might have had regarding the research was instrumental in gaining support for the project. Elder Alice Reid noted that this was important to the success of my work when she stated that presenting the research to the Health Centre would enable me 'to move freely in the community'.

As anticipated, the women and Elders who participated in the research also had many questions and concerns regarding the new HPV vaccine Gardasil. Coinciding with the Federal government's announcement to provide 3 million dollars in funding towards the programming and delivery of this vaccine to young women and girls within the school system, the conduct of this research necessitated that I spend time teaching and explaining how this vaccine might prevent the development of cervical cancer in the young women and girls. In this regard, and in working with the women who had experienced cervical cancer, I was often able to share some of my knowledge with others interested and involved in the research.

In a similar fashion, the Cree and Cree-Métis women who shared their cervical cancer stories and lived experiences were as much or more my teachers than 'informants'. This was likely due to the nature of our relationships and the reasons that the women stated they participated in the research. For example, several of the women stated that their decisions to participate in the research were largely due to the desire to help prevent this disease experience in other Aboriginal women. Further, all of the women stated that they were willing to speak publicly about their experiences if it would benefit other Aboriginal women. This idea of 'Need' as the impetus for Indigenous research can again be referred to as an essential component of Indigenous research and is found within the work of many Indigenous researchers and educators, such as Ermine *et al.,* (2004) and Meyer (2003).

Additionally, the Elders, who participated in this study as traditional teachers and keepers of cultural knowledge, also played a role as personal guides and mentors throughout the research. At times, the stories of the women would become overwhelming with the realization that they had suffered great losses and hardships in their lives. On several occasions I approached Elders to discuss these matters and gain their moral support. Further, and in relation to meeting with the women and discussing this research, sharing the information that I was seeking guidance from community Elders seemed to validate my research. For example, Elder Alice Reid planned and facilitated the seminar that I participated in with health service providers in Northern Alberta. Although her expertise as the Coordinator of Health Services validated the importance of this issue for her community and staff members, it was likely that her role as a keeper of traditional knowledge made our approach to this intimate and culturally significant topic acceptable. In other words, the staff members as Cree and Cree-Métis women trusted in Alice's judgement on the appropriateness of my topic and of my approach.

As the researcher in these processes, acknowledging these different roles of the participants enabled me to facilitate many of the processes that occurred. Showing respect for these women participants as teachers, and not just informants, in the research helped to establish reciprocity in our relationships. Building relationships with these women, Elders, and community members in the context of the research was based on the fact that we shared similar concerns and interests in relation to the health and wellness of Aboriginal women. This meant that I was willing to actively participate, learn from others, and share my knowledge as a Nurse and health service provider in the process.

### *Retracing Steps & Events of the Research*

> *Protocol takes on a whole new meaning because I am immersed in a world of protocols.... in the context of research, I am compelled to be conscious of their significance. I carry a different sense of personal responsibility when I enter the community with a research program and invite others to join me. I am saying to them, this is safe and we can gain from it. They, of course, make the choice to join or not, and they also carry that sense of responsibility and accountability to the rest of the community. Relationships drive the core of the research. Methods arise from the flow of movement as the work progresses through time and space. The researchers make decisions about today's methods based on yesterday's activities and methods. (Weber-Pillwax, 2004, p. 85)*

#### *Working with the Elders*

As outlined in Chapter three, strategies and methods were used that would work to create a safe environment and develop the relationships that would support the collection and analysis of data for this research. According to Indigenous researcher, Atkinson (2000), research with Indigenous peoples and communities that is not grounded in the practices and protocols of the people involved will often fail or give rise to conflict. Grounding research in the practices and protocols of Aboriginal peoples, Atkinson (2000) states, is "based on ethical knowledge(s) and procedures which locate the protocols of working with Aboriginal peoples within themselves" (P. 69). Therefore, the strategies and methods used throughout the study were chosen according to my knowledge as a Cree and Cree-Métis person and the past lessons that I have learned in doing research and working with Northern Alberta Aboriginal peoples and communities.

The desired collaboration between the Elder women, as traditional teachers and keepers of traditional knowledge, and myself as the researcher necessitated ongoing communication with each Elder on several occasions. Travel to several communities was required in order to achieve this. For instance, two of the Elders either work or live in Northern Alberta, and several discussions were needed to coordinate visits to both women in the same trip. Through protocols, I indicated that I was there to ask their support in some manner. Elder Rita Auger expressed her appreciation of my adherence to traditional protocol at the end of our initial visit when she stated, "This is how things should be done. One gives another something and that one then returns something to the first one".

Much of the conversation during the initial visits revolved around the mutual relationships that we held. This is an important aspect of relationship building within kinship societies (First Nations, Métis, Inuit Steering Committee and Working Committee, 2004)[19]. If we were able to get to a discussion regarding the research project in this initial visit, it was limited to who was involved at the community level and how the research would benefit Aboriginal women and their communities. For instance, each of the Elders asked questions about the Elders who might be involved. As I had planned, each of the Elders knew one another or knew of each other's work and knowledge in the area of women's health. This worked to help each Elder to decide if her own involvement was appropriate and safe. At the end of these visits, I enquired if the Elder was interested in working with me on this topic and if I could come and see them again to talk about it further. I followed this process with each Elder, including those Elders with whom I had worked with previously.

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[19] *Histories, Cultures, and Contemporary Issues of First Nation, Métis, and Inuit Peoples of Alberta* is a teacher preparation resource package developed through a collaboration of Aboriginal researchers and educators.

Following this process with each Elder worked to begin a new relationship or renew an existing relationship in the context of the research. As well, the next visit with the Elder would now have a specific purpose and would allow the Elder time to decide whether she chose to be involved or not. Entering into this relationship with me as the researcher meant that the Elder was willing to commit to the project and see it through to the end. The next steps to be followed at this point, involved staying in touch with each of the Elders and assuring them that I was sticking to my plans. This was done through either calling them on the telephone or by traveling to their community. On several occasions, the Elders I had gone to visit were unable to see me at that time. However, my presence in the community showed that I was committed to this project and to working with them.

Once the Elders decided on their involvement in the research, we worked together to refine their role in the project. As our relationships developed further, it became clear to both the Elders and me that one gathering or bringing all of the Elders together in one place would work best in the interests of time. It should again be noted that the area of women's sexual health and wellness is considered to be culturally significant among Aboriginal peoples and has rarely been discussed openly and to any great depth in the formal research arena. This may have had an impact on the Elders' decisions to approach the topic in ways that would support what they would choose to share. In this way, the manner in which I had worked to develop these relationships within the context of appropriate community practices and protocols was key to the success of the project.

Once I had gained the support and commitment of the Elders I would be working with, I began to feel apprehensive that the women who were going to be telling me their stories were somehow beginning to lie at the wayside. This was due, in part, to the extensive energy and time that was required to plan and coordinate the establishment of the Elder group. For example, my initial plan had been to interview the Elders in the area of women's sexual health prior to conducting the interviews with the women who had experienced cervical cancer. However, the Elders began to teach on topics related to Cree and Cree-Métis women's sexual health almost immediately after their decision to become involved with the project. I then visited with the Aboriginal members of my supervisory committee and through our discussions came to the realization that I had accomplished what I had set out to do for this stage of the research. These teaching sessions with the Elders, while earlier in the research schedule than I had anticipated, had provided some of the teachings I had been looking for to guide me in my interviews with the women. To interview the Elders further, prior to speaking with the women, would likely have had an impact on the interviews with the women that might have detracted from a necessary focus on their personal experiences and perspectives. I already had learned so much!

This was a significant learning for me about how working within an Indigenous research methodology framework means a researcher must be guided by the directions that evolve from within the unfolding process of relationships and events much more so than by the directions of the formal research plan. Throughout the visits and discussions with the Elders, I was always made to feel that this work was important and that I would be contributing to the betterment of our communities. Their kindness, patience, and love for their communities were always reflected in what they talked about during our visits. It became apparent that their concern for the health and wellness of the women of their communities was at the forefront of their involvement in this research.

### *Working with the Cree and Cree-Métis women*

As stated previously, it was never my intention to seek out Aboriginal women only of Cree and Cree-Métis descent. However, the activities that I participated in during this time naturally led me to these women due to the need for developing trust through the bridging of existing relationships. Seeking out these women who had experienced cervical cancer and who might be willing to participate in the research did not take place in isolation to the work that I had been involved in with the Elders. Specifically, this is because access to potential participants increased as I went to cultural events, developed my relationships further with the Elders, and entered communities to visit those involved in the study. Also, the stigmatizing nature of the topic required concrete evidence to participants of my willingness to use what was learned in a culturally appropriate and safe manner and in ways that did not stigmatize them further. Elder involvement in this process and the entire research project provided much of the proof that the women were looking for. As well, presenting my planned project to women in different communities and again the bridging of these relationships based on existing mutual relationships all had an impact on women's decisions to participate in the project.

Though it was challenging, much time and energy was required to meet potential participants. Relationship building was essential to the approach or methodology and I needed to remember that some time would be required to build these relationships. Events that supported relationship building might be as simple as meeting a participant to have coffee and learn about each other's interests, work, family, and community. However, it was often necessary to travel as many of the participants lived in different communities across Alberta. I had originally begun to look for participants through presenting my work in Northern communities. This approach, however, had not brought in Aboriginal women participants to the study. It was beneficial though in the building of relationships with Cree and Cree-Métis community members who would later support participant relationships and Elder involvement during the data collection and analyses stages.

I then spoke with my peers and professional colleagues about my project and asked if they knew of any women who might be interested in participating in the study. The majority of the participants were found in this way and the researcher-participant relationship that developed was supported or bridged by existing relationships that were mutual to both parties. This bridging or support of new relationships did not relinquish or diminish any of my own personal and ethical responsibilities in relation to the project. In fact, as cited in the methods chapter of this study, any personal and ethical responsibilities in this context would need to consider both the party who introduced the potential participant, the participant herself, and often the community that they identified themselves with (Goudreau, 2006; Roberts, 2005; Weber-Pillwax, 2003). For example, several of the participants belonged to the same communities as the co-researcher trainees who facilitated our introductions. In a cultural context or according to the ethical standards of many Cree and Cree-Métis communities that operate within a kinship system and oral culture, this meant that the facilitator or co-student introduced the participant with the understanding that they themselves were responsible for my intentions and behaviours in relation to the project and its outcomes. Weber-Pillwax (2001/2003/2004) talks about the Cree and Métis peoples of Northern Alberta and orality in stating: "powerful renderings of intense oral expression...provide the individual impetus for...a sharing that becomes the individual and personal expression of commitment to membership within and of communion with the collectivity" (Weber-Pillwax, 2003, p. 130). Although Weber-Pillwax (2003) is referring here specifically to a cultural event of Northern Métis and Cree peoples, the *wihkohtowin*, her statements demonstrate that the oral 'nature' of these peoples enable that which they consider to be significant – *commitment to membership within and of communion with the collectivity* (p. 130). All of the participants in this research were Cree-Métis and Cree women of Northern Alberta.

As a member of a Cree-Métis community myself, I was able to arrange to meet potential participants through existing relationships and friendships. Although issues of confidentiality were of utmost concern to me, I found that a mutual relationship worked equally well because we both knew and trusted the person who facilitated the introduction. Locating or identifying potential participants required trust and bridging relationships to already existing ones; the use of posters or other forms of written communication to meet Aboriginal women who have experienced cervical cancer was not practical or feasible.

I stated previously that I interviewed five women who have experienced cervical cancer during this study. Although there were originally eight potential participants, three eventually decided not to participate. Initial conversations with the women who participated discussed where our families were from, who our family members were, and if the participant was interested in learning about the project. At that time, we would then make plans to meet again and of those women that I was able to meet with on a second occasion, each began to tell their stories during the visit. All of the relationships that developed to this point resulted in the commitment to participate in the study. With the three women who decided not to participate, we were unable to form this bond of trust at that particular point in the study. I believe that this had the most impact on their decisions.

This represented one of the challenges of the research – the significance of timing. For example, if I had started to look for participants too early in the research, then people would likely have lost interest. Similarly, and in the instances where I did not start soon enough, it became impossible to develop the needed bond of trust in our relationships that would support the individual's participation and commitment to the project. It should be mentioned that with each of the five women who had participated, I was able to build that relationship very quickly. Ongoing contact with these women seemed to assure them that I would return after getting their stories. Once a certain level of trust had been reached, the women and I then made plans to do the actual interviews.

### *The Elder's gathering*

After meeting with each of the Elders, it quickly became apparent that one group meeting or gathering would meet both or our needs and objectives. The purpose of this gathering was twofold. First, I had anticipated that what I had learnt from the women in relation to their sexual and overall health experiences could be expanded upon and become even more meaningful through the Elders' interpretations of the women's experiences. In working with Elders previously and at the onset of this project, I was unsure of how this would all materialise. Although I already knew that Elders seldom work and teach from within a question and answer framework, I soon realised that I had been naive in assuming how and in what ways the Elders would contribute to what I had learnt from the women. I had hoped that they would act as co-researchers in analysing the stories of women in relation to how the Cree ways of life were manifest in the lived experiences of these women. At least, that was how I had envisioned it.

Second and through beginning the analysis of the women's stories, I found that all of the women used traditional teachings and knowledge in caring for their health and wellness. Similar to my own experiences, the majority of these women had some understanding of some of the cultural teachings and knowledge that are significant to their sexual and overall health, but have been unable to access them further. In visiting and meeting with the Elders prior to the gathering, they had already begun to talk about traditional teachings and knowledge that are significant for Cree and Cree-Métis women's sexual health. It then seemed reasonable that the further purpose of the gathering with the Elders could be accessing these teachings and knowledge. In hindsight, as discussed in chapter seven, the contributions of the Elders and their involvement in this research evolved according to their own practices and processes. Moreover, what I learnt in working with these Elders throughout this research process would be as significant as the cultural teachings and knowledge that they shared.

Due in part to the cultural significance of the research topic and in light of the many responsibilities and competing demands on the time of these Elders, careful consideration and planning was required to host a successful gathering. Planned well in advance, the gathering necessitated that I keep in close contact with those involved to ensure their continued support and attendance. At times, I almost felt as if I were badgering these women. In the end, the Elders each expressed appreciation regarding my ongoing contact with them.

Initially, it had been my intention to share portions of the women's stories or vignettes with the Elders at the gathering. This meant that the interviews with the women needed to be completed and returned to the participants for their review, reflection, and agreement. In addition, because I was aware that many of the Elders were seniors relying on fixed incomes, I needed to make arrangements for their travel and their accommodations near the University in order to attend the gathering. I did this, in part, by coordinating their attendance to other events in the same visit. A one-day session or gathering with four female Elders from across Northern Alberta was held in the spring of 2007. As well, one of the women who had been facilitating much of the work I was doing in communities also attended the gathering.

In relation to meeting the goals of the research, attending to the work and the processes that were needed to exercise commitment to these women, the Elders, and communities proved to be a worthwhile and essential element to the success of the project. In other words – access to Cree and Cree-Métis women, Elders, and communities from across Northern Alberta on a topic that is intimate in nature and culturally significant, required that I, as the researcher, participate in the groundwork needed in order to create an appropriate and safe environment in which the work could then take place. Embedded in these processes and outcomes of these processes were the principles of respect, reciprocity, and relationship building. In addition, adhering to these principles would enable the research to be successful. This would come to be realised through the paths and processes of the research that facilitated the development of relationships that were of meaningful quality.

### *Unfolding the Research Processes – Methods or Methodology?*

> *The researcher is accountable for the effects of the research on the lives of the participants, and indeed can also be held accountable for impacts on the lives of everyone in the community. This means that in choosing research methods, I, as researcher, must consider carefully not only the possible effects of my whole research project, but also the effects of each specific research method.... (Weber-Pillwax, 2004, p. 81)*

In talking about the processes that evolved during this research, I was faced with several immediate challenges in relation to working with Indigenous peoples from within western intellectual research frameworks. First, I needed to describe, in a linear manner, what was learnt from within Indigenous contexts while taking into consideration the iterative or circular nature of Indigenous knowledge and learning. This circular nature or cyclical pattern in Indigenous learning and writing is referred to in the research of Native American educator Eber Hampton (1995) and his work *Towards a Redefinition of Indian Education*. Hampton (1995) talks about the structure of his work as "iterative rather than linear" and states that in writing about this work, he became aware of how "deeply engrained this iterative structure" was in his own thoughts (p. 7). Similar to what Hampton (1995) describes, I found that my learning during this research built upon itself in a cyclical fashion in ways that enabled me to find "new meaning in each turn of the spiral" (p. 7).

Second, what was written needed to acknowledge that my learning from within an Indigenous context was more often than not what Graveline (1998) calls an "embodied experience" (p. 77). She states, "[o]ur Ancestral consciousness was mimetic and participatory. Traditionalists continue to believe that the more of our senses-sight, hearing, smell, taste and touch-that we use in learning/teaching something, the more likely we are to understand and remember it" (Graveline, 1998, p. 77). Inherent to learning in this capacity, according to Graveline (1998), is metaphoric thinking, the use of our non-physical senses such as blood memory, dreams, and visions, and the shifting or moving to another state of consciousness (p. 77). For me, as the researcher, *learning in this capacity* included all these things.

Finally, talking about and describing concepts, such as transformation and the shifting of consciousness, posed the real danger of committing further oratory blunder on the nature of Indigenous knowledge systems. For instance, Graveline (1998) cites Absolon (1994) speaking to the potential dangers in defining and describing the cultural teachings of the Medicine Wheel: "When we speak about the teachings of the Medicine Wheel there is always the danger of those words becoming rhetoric unless our talk is accompanied by an action that reflects the nature of the talk (Absolon, p. 29 as cited in Graveline, p. 76). In order to avoid producing such rhetoric, I have tried to use concrete examples or instances when possible in order to describe the research processes or themes and reflect their meanings. The methodological challenges – issues of time and energy and working from within western intellectual research frameworks – illustrate the challenges that needed to be met during this research. Each is discussed in relation to meeting the needs of this project from the perspectives of Indigenous principles and philosophies.

### *Time and energy*

As a challenge of the research, the methodology and methods needed to consider the issues of time and energy. Time and energy were often at the forefront of my concerns regarding the development and conduct of this research for several different reasons. First, as a student attending an academic institution, certain guidelines must be met in order to complete a degree. This was sometimes in conflict to the schedules and social mores of Cree and Cree-Métis peoples and communities. For example, the interviews with the women and the gathering with the Elders both occurred throughout the late winter and spring. However, the summer season for most Aboriginal peoples is a time of gathering and traveling. Most notably, by the time I was ready to return the data that I had collected and analysed to participants, the majority were away attending cultural events or visiting family in other communities. Weber-Pillwax (1999) states that, "the integrity of Indigenous peoples or communities needs to be respected (p. 23). Similarly, Martin (2002) emphasizes "honouring Aboriginal social mores as an essential process through which we live, learn and situate ourselves as Aboriginal people in our own lands and when in the lands of other Aboriginal people" (p. 5). Allowing the women and Elders time in order to go about their usual practices was important in terms of respecting and honouring them as Cree and Cree-Métis peoples. Despite my academic needs or deadlines.

Second, gaining entrance to communities required time and energy. For instance, I needed to spend a great deal of time and energy preparing for visits to communities and traveling. This was again instrumental in establishing trusting relationships, creating safe learning environments, and developing community support for the project. In addition, allowing the research and its processes to go through their natural progression with time enabled the development of relationships that would reveal new understandings of Cree and Cree-Métis perspectives of women's health; perspectives that would be grounded in the lived experiences of Cree and Cree-Métis women as expressed through privileging the voices, experiences, and lives of Cree and Cree-Métis peoples (Martin, 2002, p. 5; Weber-Pillwax, 1999, p. 23).

### *Working from within western intellectual research frameworks*

Working from within western education as an Aboriginal woman, community member, and researcher also represents some of the challenges that needed to be met during this project. This included making sense of what is taught from a western perspective to the realities of working with Cree and Cree-Métis peoples and their communities. Working from within what may be considered restrictive processes in order to rise above the stereotypes that are pervasive within our academic education and research arenas and heath care service education and delivery systems in relation to Aboriginal peoples represents the challenge that is faced on an almost daily basis during my work and the work of other Indigenous colleagues. In the final section of this chapter, I discuss these challenges in relation to what was learned during this research and talk about the significance of this for working toward the improved health and wellness of Cree and Cree-Métis women.

Making sense of what is taught from western perspectives in relation to the lived realities of Cree and Cree-Métis peoples was alluded to throughout the first sections of this research in which I identified the complex nature of Aboriginal women's health and illness experiences. I stated that this research would necessarily acknowledge these variances in the historical, social, and political environment of Aboriginal woman. One important way for the research to do this was to take the time and spend the energy that was required to carry out the activities of the research in ways that would respect the lives and traditions of the people involved in the research. What I found in trying to achieve this was that the restrictive processes and imposed stereotypes of Aboriginal women and their health required that I remain always keenly aware of the ways in which this research could impose the same restrictions and stereotypes on these Cree and Cree-Métis women, Elders, and communities. Further, some of these restrictive processes were intimately tied to the stereotypical attitudes and ideas about Aboriginal women, Elders, and their communities. For example, doing this research led me to a fuller understanding of the ways in which Indigenous knowledge systems may work to support the development of positive Indigenous female identities. This ultimately meant that acknowledging community members, such as Elders, as educators would be required during this research. However, many of the disciplines that I found myself involved with were not as willing or prepared. This is glaringly obvious in the ways in which each time the expenditure of funds to bring these traditional teachers and knowledge holders to the university to work with students or participate in the learning activities organized by other academics is always questioned in relation to its educational purposes and values. Although these restrictive and prohibitive circumstances may be viewed by non-Indigenous faculty members and educators as improving – those of us working from the outside are constantly aware of the persistent need to justify our educational objectives. In relation to my own research, I came to realise that certain questions regarding the expertise and sources of the knowledge and insights would also arise and that I needed to be prepared to defend my thinking through the research and its findings.

Upon reflection of the ways in which the work with the Elders would build on the lived experiences of the women, I was aware that the question might arise as to whether the findings were sound in stating that the stories and teachings of the Elders did build on the work with the women in the ways that I had described them. Or did they only work to validate the lived experiences and concerns of these women because the Elders involved in the research possessed similar orientations to the world? My responses to this are as follows:

1) This work relied on descriptions of Cree and Cree-Métis women's lived experiences as much as possible because I sensed that this was one way to validate my interpretations of the ways in which the work with the Elders would build upon the stories of these women [I found support for my assumptions in the work of Weber-Pillwax (2003) where she states, "descriptions are crucial…because it is impossible to rely totally on interpretations to convey meaning accurately" (p. 31)].
2) Similar cultural orientations of the Elders (to that of the women) was in fact the reason that their stories and teachings could build upon the stories and experiences of the women; otherwise, it would not have mattered if the Elders were also from Northern Alberta Cree and Cree-Métis communities ensuring that their orientations and cultural teachings would be valid in examining the stories and experiences of the women.

3) My interpretations of this data are based on the same assumptions as the participants possess in that I realise cultural teachings and knowledge emanate from sources other than and outside of ourselves. This assured me that the findings of the work with the Elders would provide deeper and more meaningful insights and understandings of the women's health and illness experiences.

In identifying and describing some of the challenges inherent in working with Indigenous peoples from within western intellectual research frameworks (such as the challenges associated with working to describe Indigenous knowledge and teachings in appropriate and respectful ways that were described in the introduction of this document), I am reminded of the ways in which this research has worked to support the research processes of respect, reciprocity, and relationship building. Again, the development of the research based in these principles had enabled me as the researcher to trust in my own knowledge as an Indigenous person, to trust in the knowledge and lived experiences of cohorts as essential to the success of the research, and to trust in the Cree and Cree-Métis women, community members, and Elders as the experts in describing and interpreting their own knowledge and experiences.

The implications of what may unfortunately be considered common approaches to health research with Aboriginal women, especially with regards to their sexual health and illness experiences, for Nursing research were demonstrated through the development of this research that provided descriptions of Cree and Cree-Métis women and their sexual health as being integrally and deeply connected with the cultural teachings and knowledge of Cree and Cree-Métis peoples. This includes the potential of Nursing as a discipline through its research to articulate descriptive findings of the significance of culture for the health and wellness of Cree and Cree-Métis women that can then work to develop nursing education and health service delivery systems that liberate other Aboriginal women and their communities from stereotypical disrespectful assumptions and further pathologizing of their health behaviours. This research, developed and based upon Indigenous principles of research and which followed the practices and protocols of the peoples involved in the research, meets this criterion through presenting findings in ways that respect and recognise the knowledge and experiences of Cree and Cree-Métis women as valid and important to women's health knowledge.

### *Summarizing Research Pathways and Processes*

In this chapter, I discussed the pathways and processes that emerged during this research project. First, I identified the research participants and described their roles during the research. Next, the steps and events of the research were outlined. In conclusion, I discussed the methodological challenges that arose during the study in relation to doing research with Indigenous peoples from within western intellectual research frameworks.

In the following chapter, I present the data analyses derived from the interviews of the Cree and Cree-Métis women who shared their stories in relation to cervical cancer experience. I begin by providing a short narrative of each woman that describes some of her life situation, as well as, her diagnoses, treatments, and procedures in relation to cervical cancer. The voices of the women are the primary sources of description and discussion in this chapter.

# CHAPTER FIVE: HONOURING THE LIVED EXPERIENCES OF CREE AND CREE-MÉTIS WOMEN

In this chapter, I present the stories of five Northern Alberta Cree and Cree-Métis women who have experienced cervical cancer. As these women were at the centre of this research, I begin by describing the steps taken to gather their stories. Next, each of the women's stories is described in relation to what I learned about their lived experiences. Then, themes or commonalities of the women's cervical cancer experiences are pulled out from the stories and discussed in relation to current research and literature in this area, as well as, particular issues or concerns that arose during my work with these women.

The stories and life experiences of these women revealed that current health systems, including delivery, has much to learn from Aboriginal peoples about how they see their own health and wellness. Although health research and literature acknowledge that historical impacts of westernization and assimilation policy continue to have deleterious effects on the health and wellness of all Aboriginal women, the lived experiences of these women are a testament to the failure of this information to reach frontline service and delivery arenas. As a primary concern of this research is protecting the anonymity of these women, their names and any information that might identify them has been changed. As stated previously, pseudonyms are used and only those parts of their stories that make a direct and meaningful connection to the lived experiences of Cree and Cree-Métis women have been included.

### *Working to Honor the Women's Stories*

All of the women were between the ages of 32 and 57 years. Each woman identified as being either Cree or Cree-Métis and each came from or resided in a different community across Northern Alberta. The majority of these women had grandchildren and their homes were often the hub and centre of familial and community activity. This demanded time beyond the average 1 ½ - 2 hours that is usually allocated to an interview. Often family members required attention and the interview process would be put on hold for a while. Each woman was given a small honorarium and gift after the interview. While this was not actual compensation time and effort, it was intended as reciprocity and to express appreciation for the sharing of their personal stories.

A brief description of each woman and her history reflects the uniqueness of each individual, both in life experience and in cervical cancer experience. These descriptions also reveal that many of the 'shared' experiences of Cree and Cree-Métis women and peoples reveal similar family histories, similar challenges, and common values and philosophies.

**Agnes** was a Cree-Métis woman who resided in rural Northern Alberta and is a direct descendent of the peoples of Battoche and the Riel Rebellion. The art work and many of the things in her home reflected her connection to the Cree and Cree-Métis and revealed that she was proud of her ancestral background. At the time of the interview, Agnes was 46, married, and had several children and grandchildren. Her home was always busy with children and grandchildren coming and going. It was clear that Agnes is the matriarch of the family and carries within her that strong sense of pride that is common to many Métis peoples.

Agnes' stories about her life and family revealed that they are hard working individuals with strong ties to one another. She mentioned that members of her family had suffered from diabetes and alcohol addiction. Although Agnes never spoke of physical, psychological, or sexual abuse within her immediate family, she did talk about a keen awareness of their occurrences in the lives of many Aboriginal peoples and stated that she had actively taught her own children ways in which to protect themselves and their families from such harm.

While I visited Agnes prior to and during the interview, much of our conversation revolved around our families, relatives, and the relationships that we held. These relationships were very important to Agnes and she spoke about what she was always learning from them. The women in her life seemed particularly important to her sense of herself and she remarked that the traditional ways in which women spent time with one another and taught one another were needed and valuable for today's generation of women. Agnes also stated that she spent time away from her family each year in order to be with other women. This time seemed very important to Agnes and she talked about the importance of the role of these other women as mothers and grandmothers and the centres of their families. She remarked that women have a duty to care for themselves as their children or the following generations will suffer the consequences if they do not. Agnes stated,

> *It's that cycle we've been taught from the time we're little. Whether it's the type of men we choose in our lives or something else. You either hit that wall and you pick yourself up or you never do. If you don't then there goes another generation. There goes her kids – because the women are the centre of the family. You [have to] pick yourself up and show your kids what a strong independent person you*

> *can be. You're their lifeblood. You're their strength. You're everything. You're their power. Do it for your children.*

Cancer had affected the lives of Agnes and her family numerous times over the years and resulted in the death of her father. Many of her aunts had also experienced cervical cancer and possibly her own mother. Many of the older women, including Agnes' mother have had hysterectomies as a result of the disease or as a complication of their sexual and reproductive health. I was surprised throughout the study to find out that the majority of the older women I met or that I had learned about were reported as having had partial or total hysterectomies[20]. Agnes and I talked about this and she told me that this had always bothered her. She stated, "My mother used to say that her hysterectomy 'is the best thing that ever happened to me'. But where is that part of me? I should die with that part of me!"

Agnes' experience with cervical cancer spanned over several years during her twenties with having undergone repeated biopsies, colposcopies, and surgery. Agnes was diagnosed twice with cervical cancer. The first time the cancer had developed to the second stage and she underwent surgery to treat the illness. The last time, cervical cancer was diagnosed in the third stage and Agnes stated that she had been slated to undergo chemotherapy. Agnes also stated that up until the time she was first diagnosed with cervical cancer, she was always told that it was "just a bad Pap". After her second diagnosis, Agnes then travelled to a small town in Alberta in order to see a traditional medicine man where she participated in the sweat lodge ceremony for the first time. Agnes remarked that she felt she knew her culture very well up until that time and that everything for her changed at that point. Agnes talked about the power that she felt was present during the ceremony and stated that her mind and decision became clear regarding cancer treatment when she came out of the sweat lodge.

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[20] Loppie (2004), in her research regarding Aboriginal women's menopausal experiences suggests that there has been an alarming rate of Aboriginal women who report undergoing a hysterectomy in order to 'fix' numerous sexual and reproductive health concerns. This includes enforced sterilization programs that were in operation in Canada during the 60's, 70's, and 80's.

Agnes was one of the two women who made the decision to use traditional medicine in order to treat cervical cancer. As she described the treatment received from this medicine man, Agnes was adamant that the reasons for its success lay primarily within her own beliefs and confidence in her decision. Agnes remarked that the medicine man had made it clear to her that the decision to proceed with traditional medicine was dependent on her beliefs and confidence in the treatment. Later in the interview, Agnes stated that knowledge and understanding of a woman's own body is critical in successfully dealing with a diagnosis and any form of treatment for cervical cancer. She stated that it is crucial that a woman understand, "whatever decision it is that you make, know that it's the right decision". Since receiving traditional medicine to treat the cervical cancer, Agnes stated that she continued to undergo yearly Pap smears, all of which have been normal.

**Madelaine** was 54 at the time of our interview. She was also a Cree-Métis woman from Northern Alberta and stated that both of her parents were Métis peoples. Madelaine's strongest tie to her family was to her grandfather. All of her fond memories that she recalled were about her grandfather. Madelaine stated that he had been a health care provider even though he had had a very limited education. She also said that she had come realise that her own sense of herself as an Aboriginal woman was always within her. We talked about 'blood memory' and Madelaine told me about some of the experiences that revealed to her a connection with her own ancestors in this manner. She spoke of feeling a great sense of loss in relation to her Native language and the traditional teachings and knowledge of her ancestors. Madelaine remarked that she felt a strong connection to this part of herself in learning to bead. She stated,

> *I learnt a lot about myself when I was taking training through [Aboriginal institution], but I just didn't realise how much of the traditional things that I knew. When I started learning how to bead, the girl who was showing me said, 'You know what, you're a Native, that's why you know how to do it. That's why. It's there within you'. I took to it like a duck to water...because somewhere along the*

> *line I had it. My great aunt did it until she died at 85. She was on my mother's side and she beaded. I think that there's a lot of the old ways in me and even with the ways that I raised my children and the ways that I interact with my granddaughter.*

Madelaine was also a single parent most of her life and spoke about herself and her children as growing up together. It became apparent that she is close to her children and very close to her grandchildren. Although Madelaine had experienced multiple diseases and illnesses in her life, she spoke about her grandchildren as being the reason she was still alive. As Madelaine spoke about her grandchildren, it seemed clear that these relationships and her connection to her grandchildren have had the greatest impact on her life. She talked about how she had felt disconnected and unable to relate to children until her first granddaughter was born.

Madelaine spoke at length about the illnesses she had experienced and continued to face. She revealed that her childhood had been very troubled and that the majority of the older women in her family had passed away at a very young age, including her mother. Many of the women in her family had undergone hysterectomies, some of which were forced sterilization. Madelaine felt that her own tubal ligation surgery at the very young age of 23 ultimately led to her having to undergo a hysterectomy. She talked about the initial surgery as being forced upon her in order to obtain an abortion at that time. Madelaine also talked about the involvement of social services in her life as a young mother and expressed anger regarding a situation in which a social worker repeatedly used coercion in order to force the outside adoption of one of her children.

Cervical cancer was just one illness experience that Madelaine had survived. For Madelaine, a diagnosis of cervical cancer was a great shock to her as it had occurred at the young age of 26. Madelaine stated that even upon receipt of a registered letter from her physician, regarding Pap smear results, she thought that the worst that could have happened was that she had a sexually transmitted disease. After learning of her diagnosis, Madelaine remarked that she knew the cancer was related to sexual activity and an STI she had been treated for. She stated, "[m]y doctor told me that the trichomonaisis had set this off". Madelaine had faced a string of sexual and reproductive health issues and after being diagnosed with cervical cancer in the second stage, she underwent a cone biopsy and surgery. Six short weeks later, Madelaine had undergone a hysterectomy.

Even though Madelaine had experienced great trauma during her childhood and early adulthood, her willingness to share herself and her story showed that she possessed great concern and compassion for other Aboriginal women. Madelaine was direct and open about her experiences with mental and physical abuse, sexual abuse, and the tragedies that had occurred during her life. Madelaine expressed great insight into the many challenges that most Aboriginal women face and stated that she would be more than willing to speak with other women regarding her own experiences with cervical cancer and what she had learnt.

**Marla,** 32 at the time of our interview, was a First Nations woman from a Northern Alberta community. She was the mother of five children, one of whom had died shortly after coming home from the hospital as a result of violence in the home. A lot of her childhood had been spent with her grandparents who had since passed on. Marla talked about her grandparents at great length and revealed that her sense of herself as a Cree person was embedded in these relationships. She explained,

> *My grandparents used to kind of laugh cause where they had their house, they had the creek not too far off and they had a sheltered area, out of the sun in the mid day. I was watching how they were. Just their locations and where they chose to live or where they did live. It was really self-sufficient to plant a garden. They had to hall it all. We never had a tractor till the early eighties. They worked with horses and they lived about 12 miles from town. Walking that's far and they used to take the tractor. We'd all be on that tractor and I remember them taking the horses too. My grandfather made a little wagon with wheels on it, real practical. All their stuff and all their grand kids would be on it, and maybe a couple of daughters too. I think back to it now, but they were so practical for those times and amazing and I got to see how they came with the evolution and some people*

> *they can't fathom living like that. I can't sometimes. We lived like that right until the mid eighties and at the same time, people were having vehicles and here we were living at a snail's pace.*

Marla had a limited ability to understand her Native language and speak Cree. She remarked that much of what she understood about herself as a Cree person was tied to her language and felt that her limited abilities hindered her at times. Marla also talked about her connections with her culture as being grounded in her spirituality through prayer and ceremony. Marla told me that she spent much of her time learning to fish and prepare Native foods, going to cultural and social events, and caring for her own needs. In talking about her own health and wellness, Marla stated that the lessons she had learned from her grandparents had been the most valuable to her in this regard. This included the need for cleanliness, proper eating habits, proper rest and exercise, and meditation in the form of prayer, dreams, and visions.

Even though Marla had had many happy memories of her grandparents, she also explained that in many ways, that was short lived. Marla's mother, who had suffered mental, physical, and sexual abuse at the hands of the church while in residential schooling, had taken Marla and her siblings away from her grandparents for long periods of time. During these times, Marla and her siblings endured these same forms of abuse at the hands of their stepfather. Not all of her siblings had been able to cope with these damaging and evil experiences as successfully as Marla. Alcohol abuse, drug addiction, mental illness, and violence were some of the lingering effects of these painful memories for Marla and her family. This was a great source of sorrow for Marla and it was apparent that she had struggled at times to overcome this.

Marla talked about the diagnosis she had been given regarding cervical cancer. Even though her own mother had experienced this illness, it was unclear to Marla if she had actually had cervical cancer until we retraced the steps and events of her illness together. She had been told that her Pap smear was abnormal on a few occasions. Then Marla's physician diagnosed her with HPV, for which she underwent a colposcopy. The abnormalities in her Pap smears continued until the condition worsened, at which time

Marla was told that she had been diagnosed at the final stage of pre-cervical cancer[21] Although it cannot be ascertained if Marla's illness had in fact advanced to cervical cancer, some literature reports that cancerous cells appear on the surface of the cervix as changes in relation to the level of precancerous lesions (cervical intraepithelial neoplasia or CIN) reach the level of CIN III (Farkash, 2005; MD Consult, 2005). At that time, Marla reported that she became fearful and had gone to see her grandfather.

Marla was the second woman who participated in this research to have reported that she had used traditional medicine in order to treat her condition. Marla's grandfather was a medicine man from Northern Alberta who practiced the use of herbal medicines to successfully treat many of the illnesses that affected his family. Although she admitted having had some doubts of her grandfather's abilities to cure the illness, Marla attributed this to the female type of problem that she had experienced. She stated, "I knew that my grandfather cured cancer and stuff like that, but I wasn't sure if he could cure my kind". Marla also said that she believed her illness had been related to sexual activity. She remarked, "[I could have] picked a better partner.... Cause that's what it was...this person I was with was with other people". Marla continued to participate in regular Pap screening and reported that since she had received treatment from her grandfather, they had all been normal.

**Marie** was 38 at the time of our interview. She also was a First Nations woman from a Northern community in Alberta. Marie was a professional who worked with people and spent a great deal of her free time looking after her home and her partner of over ten years. She had grown children from a previous marriage and was very close to her siblings. It was apparent that these relationships were very important to Marie as she had talked in length about each of her brothers and sisters. She was estranged from her father and both Marie's mother and grandparents had passed on. As a child, Marie had lived most of her life with her grandparents.

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[21] Marla was earlier diagnosed with dysplasia or changes to the Squamous Intraepithelial cells (SIL) on the surface of the cervix. It is likely that her final diagnosis was related to the presence of precancerous lesions in the cells of the cervix (cervical intraepithelial neoplasia or CIN I-III) at which cervical cancer is said to occur at the level of CIN III.

During our visit and interview, Marie stated that she had been suffering from anxiety and depression and that this had occurred several times throughout her life. She explained, "I've lost my inspiration somewhere. And I don't know what that means? I've been trying to figure that out for myself". When we began to speak about this further, Marie told me that her mother had died in a tragic accident when she was very young. She had suffered terrible nightmares for the next two years and had first attempted suicide at the young age of 11. This loss continued to affect Marie deeply and was a source of much anxiety for her in her estranged relationship with one of her own children.

Marie expressed a great sense of loss in relation to her Native language. Although Marie's grandmother had spoken Cree fluently, she had not passed this on to her grandchildren. Marie talked about her loss in saying, "But you know what's funny is that Granny never taught us Cree. She never wanted us to learn Cree so we wouldn't know what she was saying". Despite her troubled past and the many losses that Marie had experienced, she was a kind and caring woman who spoke softly and listened carefully to those around her.

Marie had been diagnosed with cervical cancer at the young age of 16. The experience had been very traumatic for Marie, which may have been further intensified by the fact that she was pregnant with her first child at the time. She recounted being diagnosed with cervical cancer in the first stage. Marie also stated that the next few months had been filled with repeated visits to the doctor for Pap smears. Finally, several months after the baby was born, Marie had been sent to a gynaecologist. At that time, the physician expressed anger in telling Marie that her cancer had advanced to the third stage. The physician had then stated that the neglect to send her for treatment earlier, meant that Marie then required surgery. These experiences only seemed to add to Marie's distrust and fear of doctors. Although Marie was never told that sexual activity could have contributed to the development of cervical cancer, she then felt certain that her diagnosis had been related to contracting the STI, trichomonaisis.

**Debora** was 57 at the time of our interview. She was a Cree Métis woman from a small Métis community in Northern Alberta. Debora's parents had both been of Métis descent. Debora and her siblings were fiercely proud of their Aboriginal heritage. This was reflected in their professional lives and the possessions that they had in their homes. Debora was single at the time although she had been married at least twice. Debora had grown children and grandchildren who played a very important role in her life. Even though her parents were then gone, the ways in which Debora spoke about them revealed that these relationships had had and continued to have had the greatest impact on her life. In talking about her mother Debora stated, "It's all a lot of my mom in me. My mom's my hero. Her inner strength, nothing got that woman down and she always had a twinkle in her eye".

Debora also spoke about the experiences that her parents and family members had gone through as Aboriginal peoples and talked about the pain that this had caused. She talked about her mother having been in a hospital isolation ward for over six months while Debora was pregnant with her first child. This had caused great stress and anxiety to Debora as she had needed to care for her father and siblings during this period. It had then turned out that Debora's mother did not in fact have TB. Debora blamed this and other experiences in her life on the stereotypes that are often forced upon Aboriginal peoples. The other incident that had caused Debora great pain in her life was the sexual abuse of her daughter. This had been at the hands of Debora's husband and it had taken her entire family many years to cope and heal from the affects of this abuse. Debora was open and honest about her own abuse with alcohol and stated, "I've been in the AA program for 12 years, so that has been a process and a revelation to just learn about me".

Debora had also talked about her chronic illness, rheumatoid arthritis, and the impact that it had had on her health and wellness. Debora stated that she was in her late thirties when diagnosed with the early stages of cervical cancer after having had a Pap test procedure. Two weeks later, Debora was then sent for a cone biopsy at which time she was told that the cancer had advanced and required surgery. Debora talked about the entire experience as having happened so fast that it had been hard for her to understand the seriousness of the situation at that time. Although it had taken many years, Debora then believed that sexual activity and the sexual activity of her partners had been at the root of this illness.

Health education for young women was of utmost importance for Debora and she talked at length about the challenges that many young Aboriginal women face in today's world. In her professional work with young women and mothers, Debora had had many opportunities to witness the destruction and damage of Aboriginal women through interference in their lives by government and social services. She felt strongly that a return to traditional values and teachings was one way to heal and combat the many negative effects of this. In talking about the issue of self-esteem among Aboriginal women, Debora stated, "We weren't given that sense of self-esteem when we were young. [But, it's there. It's there in our culture]. That's the old ways. The beautiful old ways".

The stories of these women revealed their individual strengths and the many challenges that they have faced in their daily living. Throughout these experiences, it was the women's own sense of themselves as Cree and Cree-Métis individuals that was most often credited with having given them the strength to endure hardship. Whether they spoke about this in terms of their relationships with passed relatives or in terms of their connections to ancestors through blood memory and visions, all of the women felt that family and these relationships were integral to their health and happiness.

The women's stories also provided evidence that living in today's world as Aboriginal women continues to have deleterious effects on health and wellness. Abuse and violence were prevalent in the experiences of these women and reminds us that there is a great need for healing to occur in order to be healthy and well. This need was especially emphasized in relation to sexual health and wellness. This is further supported by the realisation that the stories of these women were recounted in a manner that suggests the women viewed their experiences with cervical cancer as only one illness that affected their overall health and wellness. Moreover, it was the long-term effects and what those implied for sexual and reproductive health and wellness that caused them the most concern.

### *Themes of Aboriginal Women's Cervical Cancer Experience*

As mentioned previously in the first two chapters of this work, the research and literature specific to Aboriginal women's experiences with cervical cancer has focused on its prevention through the promotion and participation in cervical cytology screening, more commonly known as the Pap smear. For instance, Wilson (2002), during her Masters research with First Nations women of Onion Lake, Saskatchewan, describes those factors that influence participation in Pap screening and finds that barriers to cervical cytology screening for these women included cultural health beliefs, feeling physically or psychologically uncomfortable, and feelings of embarrassment (p. 40). (This research study was designed to understand and articulate the lived experiences of Aboriginal women in relation to cervical cancer in the context of their sexual and overall health.) Although Wilson's (2002) findings are similar to this study in that these women alluded to feeling physically or psychologically uncomfortable and having felt embarrassment, the following discussion of themes based on Cree and Cree-Métis women's cervical cancer experiences presents these experiences as being grounded solidly within the larger context of their overall health and daily lives.

#### _Pain and fear_

All of the women talked about pain and fear during their experiences with cervical cancer. Physical pain was always referred to in relation to the procedures that the women had undergone and the pain was viewed as necessary in order to deal with the situation. For example, Madelaine stated:

> *It hurt. They take little pieces. They take a little biopsy. I thought it's not going to be that bad. It's like well maybe you should have it done. And it's a male doctor telling you that. So I went there and they had a teaching thing going on. I don't know why but I always seem to have this doctor that has a trail or team after them. He was showing them and I just knew in my heart that that's what it was. He said*

> *there were these little white pieces there and that's where they had to clip from. Well with the whole class there you don't feel like you want to talk to anybody. I thought it was kind of degrading and I didn't want to say anything. I just took it as being part of what I had to do to find out what was going on.*

Similar to the experience that Madelaine described, the women all talked about physical pain in describing the following procedures: biopsies of the cervix in order to determine the current stage of diagnoses; colposcopies to treat pre-cervical cancer and cervical cancer diagnoses in which the outer layer of the cervix is frozen and expected to slough off; loop or laser surgery in order to burn off the cells on the outer layer of the cervix that are visualized as being cancerous; and, hysterectomies where there is a partial or total removal of the reproductive organs of a female, both of which include the cervix. This may be of particular significance as the cervix is said to be free of nerve endings; thereby, suggesting that health professionals may not be taking as many precautions to guard against pain and discomfort in performing procedures on the cervix as they may be taking in performing other procedures (Sohan *et al.*, 1999).

Each of the women described the associated treatments and procedures that they had experienced in relation to a diagnosis and treatment of cervical cancer. All of the women, except for Marla, were diagnosed with cervical cancer in either the 1st, 2nd, or 3rd stage (referral to chapter two describes the ascending order of the four stages of cervical cancer). Marla was likely diagnosed with pre-cervical cancer at the level of CIN III. As stated in Chapter two, "The incidence of cervical cancer is said to occur when malignant tumour cells within the cervix or surrounding tissue or organs indicate the presence of precancerous lesions at a level of CIN III, or the most advanced level of cervical intraepithelial lesions" (Canadian Cancer Society, 2004).

The absence of physical pain during treatments and procedures was also talked about by several of the women. Surprisingly, the absence of pain did more to add to the fears of these women and often led them to believe that they should have taken drastic measures in order to avoid pain and complications in the future. Marla stated:

> *I wasn't having any pain. All these things that they said and I thought to myself, everything seemed normal. And then all of a sudden from one test (snaps fingers) they want to do this laser surgery. I should have went for my second opinion, but it scared me so bad.... I'm happy now cause you don't know what that burning is going to do to you [the burning sensation often experienced during treatment procedures for pre-cervical cancer and cervical cancer, such as a colposcopy]. At that time I thought that's going to hurt. Why don't I just get a hysterectomy? That's what I thought.*

Fear and uncertainty regarding the future was expressed in this excerpt. Like Marla, each of the women talked about their fears in relation to the future. This included fear for themselves and the future of their families. For the women, as individuals, fear was talked about in relation to the loss of independence. Marie explained:

> *I never thought about being sick and the first thing I think is no independence. No independence and everybody having to take care of me when I've got so much to offer everybody else. So when I'm sick, I'm scared everybody else has to work harder. That's what I think. I think if I don't take care of myself then everybody has to take care of me.*

Debora, a working single mother stated:

> *I don't have anybody else taking care of me and it's scary out there for a woman my age.... I didn't have anything to fall back on at all. It was me. That was it. That's fear.*

Two of the women were diagnosed during pregnancy and described their feelings as overwhelming and fearful for the future of their unborn children. Agnes stated:

> *I was just petrified [when I was told I had cancer] because I was pregnant. Being pregnant made it worse.*

Feelings of fear and an uncertainty about the future were exacerbated during pregnancy as Marie explained:

> *Finally I was probably 6 months pregnant and the doctor said, 'okay your cancer has advanced. You're in the 2nd stage now'. So he gave me this pamphlet and there was nothing they could do until I had the baby. I said, 'Is it going to spread to the baby?' And they said, 'Not likely'. But that's why I had to keep going in for check ups. Over and over and over again.*

Agnes spoke of being petrified after learning that she had cervical cancer. For the majority of these women, fear and anxiety in relation to a diagnosis of cervical cancer was intimately tied to the future of their children and families. Debora, a single mother at the time explained:

> *So I went in and the doctor said, 'There are some signs here. There's some growth in your cervix and its cancer'. And that's all I heard was that word. I was just like wow. I broke down. I was in shock. I was just in shock. Nobody was here. I didn't have any family here. My family was all living away. Consequently my kids had nobody. Cause if I died, they didn't have their father. They had nobody. I was very scared....*

Marie also explained how experiencing cervical cancer caused her to have a sense of 'urgency' about the future as a woman and a mother when she stated:

> *I would imagine that there are a lot [of girls getting STD's] because I truly believe a lot of girls even these days are not using protection the way they should. I feel really sad if they don't take care of themselves. Do something about it. I*

> *think [its urgent]. Absolutely because for as quick as I went through the stages I went through...you never know cause it was only like within months. I have to [get a pap now]. You don't have a choice as a woman who needs to take care of herself, who wants to watch their children grow up and see them have children before you leave. Yes. You have to, whether you like it or not.*

Debora explained that the word cancer itself induced feelings of fear and an anxiety about the future. She stated:

> *Cancer is like a word that unless you know what it sounds like connected to you...my first sponsor died of cancer and she was taken within months. Before that, I knew nothing [about cancer]. Nothing.*

Madelaine mirrored these sentiments when she explained:

> *I felt fear. No matter what they said that it's the easiest cancer to treat, there's still that fear when you hear cancer. So I just did it and I didn't share it with anybody. But that was how I believed I had to behave and that's how I was raised.*

Marie also talked about being fearful when she was given a diagnosis of cervical cancer and talked about how it had affected her husband when she stated:

> *There was no explanation of how or why or what it was or what caused it. They said it was cancer. Cancer was cancer. I knew what cancer was and that it could be fatal. I wasn't as afraid as my husband was cause he came in with me when I got diagnosed.*

Similar to Marie, Agnes explained that her diagnosis and experience with cervical cancer had also had a profound effect on her husband:

> *I also have my husband. He's my best friend. We'd talk right into the night, him and I. Right from the time that we decided to get married we were a team. We're the same person. When I went through this, we went through this together. It wasn't just my cancer. It was his. He was petrified. Really, really scared cause we didn't know anything about this. I didn't realize how badly it affected him till one girl that was working for him got diagnosed with cancer. She went to him and said that she needed some time off for these procedures. He fell apart in his office and he explained to her that I had gotten through this. So he actually got to talk about it and he helped somebody else.*

Marla talked about the impact of her diagnosis on her entire family when she stated:

> *I didn't understand that it was pre-cervical cancer cause I didn't want to. I didn't want to scare myself into this cause I knew that it could get really ugly. I knew in my mind that if you let something run, then it's going to go. The gravity of it. My whole family knew and they started freaking out. I told my mom and then she told my whole family, of course. They were more or less digging my grave.*

Marla talked about not understanding the gravity of her situation. Like Marla, all of the women expressed fear and anxiety for their personal future, the future of children, and of family. This fear was often expressed in terms of shock and bewilderment. Marie explained:

> *I just went in for a pap smear and they called me in and said you got cervical cancer. And I said, what? I thought cancer was cancer.*

Fear and anxiety were also expressed in relation to having had the experience. There was fear in having had the experience and being aware of the possibility of cervical cancer. Debora stated:

> *I don't want to live with that fear [of being aware of cancer]. I'm going to do what I have to do. I listen when I have to. I have to say, I am aware of it okay. It is a fear, on some level. I don't want any self-professed prophecy happening here, so I avoid thinking that because I had it once, so I am prone to that....*

As stated previously, literature and research in the area of cervical cancer tends to focus primarily on prevention through participation in cervical cytology screening. Although the experiences of cervical cancer are largely talked about in relation to diagnosis, absent from the literature is a description of Aboriginal women's experiences at different stages of the disease. Fear, apprehension, and anxiety were expressed by these women, no matter the stage at which the illness was diagnosed and regardless of the manner in which they learned of the diagnosis. Marla, diagnosed with pre-cervical cancer or the level of CIN III expressed feelings of fear and anxiety similar to Agnes who had been diagnosed multiple times. Marla explained:

> *I didn't go see a gynaecologist. I went in for a test at the hospital and then after about a month, they phoned me back. So I went and got the biopsy done and I thought everything was okay, it wasn't a big thing, but I was still kind of scared about it. Who wouldn't be when they're reading this information? [pamphlets on cervical cancer she was given after the biopsy]...then they told me that I had the 4th stage of pre-cervical cancer and then that's when I really started getting scared.*

Unlike Marla, Agnes' story revealed that she had experienced a progression in her illness to more advanced stages of the disease on two separate occasions and that surgery had been required for a diagnosis of cervical cancer in the second stage. Although Agnes stated that she had gone for colposcopies at least six times, it was not until the need for surgery arose that she became fearful. She explained:

> *And then I said to my doctor, 'Well, when are you going to book me for the colposcopy?' But my doctor said, 'No. Not this time. We're going to send you for surgery'. That's when it scared me.*

Debora, who also underwent surgery for cervical cancer stated:

> *It was the early stages because they were going to laser it. That's what I heard. I phoned my mom and talked to her, so she came and we took the bus to the Hospital. We got there and I went in and the doctor just examined me and he took off his stuff and he said we'll have to go in. And he started explaining the cone biopsy, cause it had spread too far and they couldn't laser it anymore. So now I'm going from its just nothing to all of a sudden it's something different. Then I had to go in for surgery after that. With a cone biopsy, they just cut around the inside of your cervix and there's bleeding after that. I was out. I was out.*

Although Marla did not state that she was given an actual diagnosis of cervical cancer, her level of fear and anxiety seemed to be similar to what Agnes and Debora both reported. This is further reflected in the following statement by Marla:

> *The doctors get mad at me cause I go every 6 months to a year and they don't want to do it that much. But I told them that I had one abnormal one so I go in every year and I won't take no for an answer. I hate it too, but I think to myself that I'd sooner have that done, only an embarrassing 10 minutes than the [alternative].*

Fear and anxiety – were the two emotions that the women attributed to their experiences with cervical cancer over and over again. These emotions or feelings are likely universal for anyone facing a cancer related illness and are certainly found within the literature and research on Aboriginal peoples and cancer (Roberts, 2005), Indigenous women and cervical cancer (Pan American Health Organization, 2000), and specifically, Aboriginal women and cervical cancer (Chaudhry 1998; Wilson, 2002). Similar to the findings of Wilson (2002) and Chaudhry (1998), the findings of this research showed that fear and anxiety are intensified due to the intimate nature of the procedures associated with cervical cancer. For instance, Marla referred to the embarrassment that she felt was necessary in order to keep a check on her diagnosis and Madelaine talked about how her experience was 'degrading', but necessary, when she stated:

> *I don't know why but I always seem to have this doctor that has a trail or team after them. He was showing them and I just knew in my heart that that's what it was. He said there were these little white pieces there and that's where they had to clip from. Well with the whole class there you don't feel like you want to talk to anybody. I thought it was kind of degrading and I didn't want to say anything. I just took it as being part of what I had to do to find out what was going on.*

Pain, fear, and anxiety have been shown to play a major role in the cervical cancer experiences of these women. Further, feelings of fear and anxiety seemed to be intensified in light of the women's absence of knowledge or limited knowledge of cervical cancer. Agnes stated:

> *Before I got cancer all that I knew was that you died. And I didn't know that there were specific types of cancer.... I didn't know much about cervical cancer. I kind of knew a little bit about my body, but I didn't really know the inner workings of my body until I did the research. I knew I had a cervix, but where was it? I knew I had a uterus, but where is it? Where are all these parts on my body? So it actually was really informative. I got to understand my body.*

The ways in which the women talked about their feelings of pain, fear, and anxiety during their illnesses revealed the significance of these emotions in their cervical cancer experience. The information that the women had been given during their cervical cancer experiences seemed to have had a direct impact on the fear and anxiety that they had experienced. For some, the experience was transformative as described here by Agnes. However, the women always revealed that they often became frustrated during the experience in relation to how much and what information they had been given regarding the illness, its development, and the associated treatments and procedures. Representing another commonality or theme of cervical cancer experience for Cree and Cree-Métis women was the lack of information provided to these women as discussed in the next section of this analysis.

### *Information and understanding as elements of cervical cancer experience*

Evidence that information, knowledge, and levels of understanding have a direct impact on the fear and anxiety that clients experience during all aspects of illness abounds in health research and literature. Children and even adults exhibit elements of fear and anxiety prior to having a vaccine or undergoing a procedure for the first time. The skilled nurse knows that providing information and assessing client levels of knowledge and understanding prior to these experiences usually allays many of their fears. However, all of these women reported that they had been given little or no information in relation to the disease and its different stages of care. Further, a majority of the women had come to expect that this was a normal part of such an experience. For instance Madelaine stated:

> *They didn't really give you a lot of information. They told you what they felt you needed to know. And that was it.*

Similarly, Debora explained:

> *I didn't probe. I didn't probe, but this was also in the 70's and the doctors weren't talking that freely about anything either. They didn't do consults like that. They weren't open with what you should know. I mean you see [where your cervix is] in science but that's because you get that little diagram with the tampons.*

For these women, their expectations regarding the little or no information that they had received on cervical cancer was most often attributed to the fact that their physicians were not female and therefore not as open or empathetic in discussing the matter. Agnes stated:

> *He wasn't as forthcoming, because it's a male doctor. Now I will not see a male doctor. I want a female doctor. I want somebody who knows what it's like to have her period, what it's like to have menstrual cramps and all the stuff that goes with it. They may not have gone through the same things I've gone through, but there are a lot of similarities and they can sympathize with you more than a male doctor.... They have more sympathy for you.*

The lack of information that these women had received during their experiences may have contributed to their understandings of the disease itself. In fact, all of the women spoke in detail of interactions with health and service providers during their experiences. What emerged as significant and important to the women was access to information and the willingness of health service providers to provide information. For instance, Agnes had an extensive family history of cervical cancer and stated that she had had as many as six colposcopies leading up to her diagnosis of cervical cancer. Yet, she revealed in the following excerpt:

> *Out of all of us, I'd say I got the furthest into it. I have 3 aunts and my sister in my family that have had cervical cancer and have ended up having colposcopies. I think that's as far as they went. My sister possibly had 2 colposcopies. I've probably had at least 6. I don't know. I lost count. It seemed like every time I went in I was having one done.... I just thought it was a bad pap smear. That's all it was called is an abnormal pap. They didn't tell me that [it was cancer and what could have caused it] till I had to go for my biopsy. It's a virus. It's no different than lice.*

Similar to Agnes, Debora referred to a lack of information in her statement:

> *They said the doctor is going to laser it out and it will be day surgery. Anyways it was minimized after that or at least that's what I heard. But the word was scary as hell....*

Debora talked about her diagnosis as having been 'minimized'. All of the women alluded to the ways in which physicians and health care providers may have minimized the seriousness of the illness. Madelaine talked about the information she received from her physician:

> *Even with cervical cancer, the doctor explained to me that she had this woman come into her office when she was stage 1, plus 1. She didn't see her and then one day she ran into her in the grocery store and she could smell it on her. She said it was at stage 4 and she still survived it. She was trying to reassure me. My mother and my aunt had it. They both had hysterectomies. My mother died from infection when she was about 30. Maybe she had it for a while.*

Madelaine further explained that it wasn't until she had received a registered letter from her doctor that the situation seemed to be serious. She stated:

> *Then they sent me this registered letter and it frightened me. ...it wasn't until it was a registered letter that I took it seriously. Okay what's wrong? And I went in and she said that I had plus one stage of cervical cancer. So they sent me to cross cancer and they did all of their tests....*

Agnes also referred to how the seriousness of the disease may have been minimized through experiencing repeated procedures and treatments. She stated:

> *I was diagnosed when I was 21 or 22. It started right around the early eighties. All the abnormal pap smears and the biopsies and the colposcopies. It just seemed like they all followed one another and every 6 months I was going in. So I think you become desensitized and then it's no big deal.*

As well, Debora talked about how she had not perceived the seriousness of her situation until she had experienced complications associated with the medical procedures. She explained:

> *They packed me with gauze, but forgot to take it out and I had this stuff that was coming out afterwards and it was like clotting and discharge. I just thought it was discharge because the gauze had separated and you only get one layer of gauze or maybe two layers of gauze. It looks like it could be discharge, because they said there would be blood clots and stuff like that and that's what it looked like, was old blood. I went back to my family doctor just a few days afterward and he found that out. I can't remember if he put me on anything for that. He just wanted me to rest. I wasn't as appreciative of the actual seriousness of the situation because when I came out of the operation, as far as they were concerned, they got everything.*

Even though these women were able to describe the tests and procedures that they had undergone in some detail, they each referred to a lack of information as contributing to what they understood about cervical cancer, even at the time of the interviews. For instance, Madelaine attributed her diagnosis to having undergone a tubal ligation. She explained:

> *I use to think that people who had tubal ligations got cervical cancer. That was a big thing because I know so many women who got the tubals and then a couple of years later they got the cancer. That was my only bit of research. Just women that I knew and even women I met in the hospital. My mom had the tubal. My aunt had*

> *the tubal ligation and they both had it within 2 years. And that's what happened to me within 2 years.*

An apparent lack of information, whether it is in relation to the women's understandings of cervical cancer as a disease and how it is diagnosed, progresses, or is treated, has been shown to have had an impact on these women with regards to their illness experiences. Similar to the findings in research and literature regarding barriers to cervical cancer screening, these findings suggest that health care service providers are failing to recognize the potential concerns of Cree and Cree-Métis women in relation to cervical cancer (reported as system barriers), a lack of knowledge regarding pap smear purposes and processes does impact Cree and Cree-Métis women's illness experiences (reported as cognitive barriers), and that issues associated with femaleness and the female body (reported as emotional barriers) affect Cree and Cree-Métis women's lived experiences with cervical cancer (Band *et al.*, 1992/1995; Hislop *et al.*, 1996; Sierra-Torres *et al.*, 2003; Solomon, 1998; Wilson, 2002). However, the level of the impact is not well articulated or understood. For example, Agnes stated that until recently, she blamed the illness event on herself and her own body. She explained:

> *For 15 years I assumed that my cervical cancer was because of me. Not necessarily something that I could put my finger on. My body's the one that decided to have this cancer flare up.*

As well, Marla also talked about the impacts and long-term effects of her experience when she stated:

> *Because...I think to myself that if I'm with a man even now I'm scared. Even now with that scare that I had with the cervical cancer, I think to myself that I won't be with a man in that traditional way, because even now I'm scared that that will become active. Not active. But activate.*

Madelaine talked about the impacts of her experience as 'striking fear into your heart' when she explained:

> *I didn't know anything about this type of cancer, basically that you just had hysterectomies and that was it. My mother had had it. My grandmother had died of cancer. My grandfather died of leukemia and I didn't even know then that that was a form of cancer. If you didn't take care of it [you could die] because my mom had survived it and so did my aunts. Still just hearing that word, it just strikes fear into your heart. I still don't know lots. I know a little bit about what I had. I know a lot of cancer is a little bit treatable more now and it's not a death sentence anymore.*

Marie talked about her experience as traumatic and her treatment as having been invasive. The experience, for Marie, was so traumatic that it had deterred her at times from what she realised is the appropriate follow-up for cervical cancer. Marie explained:

> *He actually did it right in his office. A colposcopy and he froze the cells and it seemed like forever. They freeze it on there slowly and then let it sit for however long. I don't remember how long it was. It seemed like hours, a couple of hours I think. And then slowly he'd go in as it thawed and slowly pull and then the cells are suppose to slough off on their own. That was the only major treatment I had for cervical cancer and then after that I was suppose to go in every 2 weeks and then once a month and then every 6 months. But I've been really stubborn. I haven't had a check up since I've been with [my current husband]. I hadn't had it. Because of the trauma of so many, it's just that whole thought. It's invasive. It's painful and you're there and you got this weird strange doctor and you know you have to do it. You know it has to be done, so you just do it right. I just hated that. I'd had enough of it. And back then they still had the stainless steel [forceps]. Now they're plastic. They're disposable. They throw them out.*

That the trauma experienced by Marie may have been magnified due to her pregnancy at diagnosis is significant. Agnes also talked about being pregnant at her diagnosis and how that seemed to have worsened the entire experience. What Marie also revealed in her story is that she felt her doctor was negligent in deferring treatment till after the baby was born. Had Marie been given enough information about her illness and its treatments, this may have been avoided. Marie recounts:

> *They said there were 3 stages and at that time they told me that was just the first stage, not quite close enough to the second stage, but close enough to be concerned. So, I had to go in every week and I got so sick and tired of [it]. I just hated it. Then they said come in every 2 weeks and then every month. Finally I was probably 6 months pregnant and the doctor said ok your cancer has advanced. You're in the 2nd stage now. So he gave me this pamphlet and there was nothing they could do until I had the baby. I said is it going to spread to the baby? And they said not likely, but that's why I had to keep going in for checkups. Over and over and over again. Probably 2 months after I had my daughter, I had to go to a specialist because the doctor said, oh, oh, something's wrong cause it's getting worse. So I went in to see the specialist and he had a fit. He was so angry. He said what kind of doctor do you have? He actually swore. What the hell was he thinking? Why did he not send you in here months ago? I said I had to have the baby first and he said that doesn't matter. You should have been here already. He was so mad. So they treated me right away.*

Debora, like all of the women interviewed in this study, stated that the experience of cervical cancer had had some lasting impacts on her life. In the following excerpt taken from Debora's story, she talked about how the experience had also affected her daughter:

> *I don't think my mom ever got sick. I mean she had major health problems. She had miscarriages and had to have a hysterectomy. I've had problems with my*

> *periods. My daughter has problems with hers. The girl's in her thirties and has to take time off work. That's how bad it is. And of course because of the cancer, any irregularity for her and she's known about the family history and my family doctor is her family doctor, so she gets the pap tests and that.*

The stories of these women suggest that the minimal information or a lack of information that they had received during diagnosis, procedures, and treatments contributed significantly to their fears and anxieties in relation to their experiences with cervical cancer. This lack of information may also be viewed as contributing to a reinforcement of fear and mistrust of health care services and service providers. In the next section, fear and mistrust of health care services, service providers, and education are shown to play an important role in the cervical cancer experiences of Cree and Cree-Métis women.

### *Fear and mistrust of health systems and service providers*

Although fear and mistrust are viewed as elements or impacts of the historical experience of Aboriginal peoples with European civilization and westernization, little research has attempted to articulate these impacts on the contemporary experiences of Aboriginal women and their sexual health, especially using their own words and stories. In this section, the words of the women reveal their fears and mistrust of health services, health service providers, and health education and show that this mistrust contributed to their present beliefs and understandings of cervical cancer, its diagnoses, treatments, and procedures.

All of the women spoke about being an Aboriginal person experiencing an illness. For instance, Agnes talked about cervical cancer as a virus and likened it to having head lice. She stated:

> *It's a virus. It's no different than lice. My god! Everybody dances around that and it runs rampant throughout our school system. Twenty or thirty years ago, it's cause you were dirty. They are still stereotyping people. You are Indians.*

Debora also talked about the stigma associated with certain diseases and being Aboriginal. She explained:

> *That same thing happened to my mother. She was put in the Aberhart Memorial for a year. She wasn't old, she would maybe have been about 50. Still at that time, it was a stigma. It was a stigma and they just assumed that because she had lung problems that she had TB and she was Native. It was a Native disease that was very prevalent or a disease that was prevalent within the Native community and the Charles Camsell of course was the northern community hospital, so they'd fly everybody down from there and what were they doing? There was 65%, they said Aboriginal in the Aberhart and it turned out to be something entirely different.*

For Marla, she described fear and mistrust of health care service and service providers by stating:

> *I feel like one test shouldn't prove it all. Not to fear cause mistakes are made. It might be. I just don't have a 100% faith that all these tests are right. I think that sometimes they just scare people into thinking that they do [have a disease] and then they get sick. I often thought that maybe they lied to me. In some ways I feel that way and not in others because of the way that they wanted me to get this done without question.*

Throughout her story, Madelaine also revealed that she continued to have doubts regarding the treatments and procedures she had received for cervical cancer. She explained:

> *I had a friend of mine years ago who had cervical cancer. They treated her and they put some kind of balls inside her. That's what they did for her and I thought oh god I wished they had that for me cause I felt like I had been cut in half. And that sounded so much easier.*

At the time of this research, Health Canada had just begun to launch its promotion of the federally funded HPV vaccination program regarding Gardasil. This had several implications for my research. First, the women all expressed an interest in learning and understanding what this vaccine was and how it could prevent cervical cancer. Second, as women and mothers, the women who were interviewed during this study, the women Elders who participated in the study, and the women in communities where my project had been introduced, all wanted to understand how the HPV vaccine might affect the young women that they knew. Further, all of the women that I talked to during this research felt that the information that they were being given was either misleading or incomplete. For example, all of the women who were interviewed in this study talked about what they felt is misleading and incomplete information being given to young women in relation to cervical cancer. The most significant factor that they identified as being misleading or incomplete was the information regarding the relationship that is believed to exist between the development of this disease and sexual activity. Madelaine alluded to this connection when she explained:

> *Then they gave me a pap test cause you had to do that and then they gave me the medication. ...I think I had to go back to have another one done just to make sure it had cleared up and then that's when they discovered that it hadn't and that's when she tried to call me to come in. I didn't even think about it. I mean at 26 you're not thinking you have cancer and when I did find out, it was like, what's the worst that can happen, it's an STD right?*

Agnes also referred to what she believed to be a connection between cervical cancer and sexual activity. She explained:

> *I did not know that it was sexually transmitted.... I didn't have lots of sexual partners. I assumed that we were doing everything right. When I first met my husband, we used condoms. Back then you used them to protect yourself from getting pregnant. But I had no idea. I knew nothing about cervical cancer.*

Similarly, Debora referred to the role that sexual activity may have played in the development of her cervical cancer when she said:

> *I never knew what caused it. I thought it was the luck of the draw. The luck of the draw, but I was also sexually active. Education again, it comes back to that doesn't it. That should be part of the explanations that we give the kids. Not only do you have sex, but you get pregnant and these are other things that can be the result of it.*

While only one of the women stated that her illness was in fact reported to her as being caused by a sexually transmitted infection or STI, the information that these women had been exposed to recently regarding HPV and Gardasil reinforced what the majority of them already believed – the existing relationships between the development of cervical cancer and sexual activity are not being fully disclosed to women and what is being disclosed to women, is poorly understood by women. For example Madelaine stated:

> *My doctor told me that the trichomoniasis had set this off. I've already gone over 20 years now and I don't think about it much now. I didn't understand it exactly but when these commercials started playing then it just came together. There definitely needs to be more known about it. More education. With the commercials, that really clicked cause I never really associated the reason why and then when I saw that commercial I thought wow but they're not seeing the whole story.*

Marie stated that it wasn't until she saw the information on HPV and Gardasil that she realised that a relationship existed between cervical cancer and sexual activity. She also reported that she had contracted a STI just prior to her cervical cancer diagnosis, which was never addressed by health care service providers in any way. She explained:

> *...not once ever was there anything about a STD. You never ever hear that. Not one doctor, not one person who's ever had it and you'd think that anyone, if you had sex once it could probably happen to you. Because there was never any explanation or you could have got it because of this or you could have got it because of that.... I didn't really ask, because to me if you have cancer, its cancer. It's cancer.*

Even in light of an apparent, albeit recent, willingness and openness to address the relationship between sexual activity and the development of cervical cancer, (on the part of health care services and education), these women remained doubtful that they were receiving the whole truth of the matter. Marie stated:

> *When they came out with this vaccine against cervical cancer and all these girls should be immunized between 12 and 24 or whatever it is. I think that they almost put fear into most, but yet they don't fully explain the whole thing. It's scientific and it's just a research thing. It's never the full story. They're not going to tell you unless you need to know. Or on your own or within your own education or as much as you're concerned, which a lot of girls now a days, I see, aren't. I think they're more sexually active now than they were when I was their age. I mean all it takes is one partner not multiple.*

In this excerpt, Debora also revealed that she felt doubtful women are receiving complete and accurate information in relation to cervical cancer and sexual activity when she explained:

> *I haven't met anybody who's had [cervical cancer]. If there are, I don't hear about it. What I have heard in the last few months is the TV ads. How they describe cervical cancer as just a couple body warts. I think that's wrong. This is a disease and nobody knows how to cure it and I think its individual. [To me, it's not clear]. Absolutely not. Absolutely not. To me it's a false message that you're sending.*

What seemed to be really unclear to these women, women who have personally experienced cervical cancer, was the relationship that exists between HPV infection and the development of cervical cancer (an explanation of the relationship between HPV infection and cervical cancer incidence is found in Chapter two). This was exemplified in the following excerpt taken from Marla's story:

> *I had started dating someone new and I came back, but we were using protection and they told me that I had HPV. I was like, HPV? What the heck is HPV? They explained it to me and right away I got scared. They said that it was a transmittable cancer. They had a sheet explaining that it was a virus that could turn into cancer.... Then they told me that because it showed up on the pap smear, that they would have to send me for a biopsy. So they sent me to the hospital.*

In her story, Marla stated that she believed HPV to be a 'transmittable cancer'. This is similar to most of the women and their stories wherein they reported that they were often unsure if it is the HPV infection that is sexually transmitted or the cervical cancer itself. For example, Marie stated:

> *I haven't really thought a whole lot about it and I've read a little bit about it. I didn't think there was a way to really prevent [cervical cancer] until recently when I learnt that it was a sexually transmitted disease and that scared me. It's a virus.*

Regardless of what may have actually caused the illnesses for these women, their words and stories revealed that their fears and a sense of mistrust towards health services, health service providers, and health education were reinforced by their experiences. The impacts of fear and mistrust on the contemporary experiences of Aboriginal women and their sexual health should be of utmost concern to health services, service providers, and health education that are intended to work with Aboriginal populations and communities. Fear and mistrust are shown here to have had significant effects on the women's present beliefs and understandings regarding cervical cancer, its diagnoses, treatments, and procedures. Moreover, the women's beliefs regarding the connection between sexual activity and cervical cancer need to be further explored in relation to this impact on health and wellness. For example, it may be helpful to discover if these beliefs stem from traditional ancient Indigenous knowledge related to sexual health or if the beliefs are related to information currently emphasized regarding sexual activity and the development of cervical cancer. In either case, the potential for the further stigmatization of Aboriginal women regarding these issues should be of great concern to health research as the feelings and affects of stigmatization on the cervical and sexual health of Aboriginal women have already been well established.

### *Chapter Discussion*

Several issues arose as I began to complete the women's interviews; however, I chose to approach these only after each woman had had the opportunity to tell her story with minimal interference. After completing 3 interviews, questions began to emerge related to the following: the role of health education in the prevention of cervical cancer disease and illness; the role of sexual activity in the development of cervical cancer; the use of traditional medicine in treating cervical cancer; and the women's knowledge of traditional lifestyles and practices in the prevention of cervical cancer disease and illness.

### *The role of health education in cervical cancer prevention*

Cancer, for all of the participants, was a disease that affected many of their family members. Leukemia, lung cancer, colorectal cancer, thyroid cancer, ovarian and uterine cancer were all reported by the women to having had occurred and been the cause of death for family members. Cervical cancer was reported by 3 of the 5 participants to have been the cause of death for mothers, grandmothers, aunties, nieces, sisters, professional peers, and friends. Of those participants who reported a family member to have died from ovarian or uterine cancer, they were unsure if these cancers had in fact started as cervical cancer or were the end stages of cervical cancer that had spread to the nearby organs.

All of the female participants but one reported that they continue to have regular Pap smears in order to monitor their cervical health. All of the participants were smokers at the time of diagnosis and reported that they continued to smoke at the time of the interview. Each reported that this was an ongoing concern for them in relation to the future development of cervical cancer. For example, Debora stated:

> *This has been very enlightening for me. Just that one piece of information that I now have, I can do some research of my own because this will help me in what I'm doing in my work. I don't want to live with that fear [of being aware of cancer]. I'm going to do what I have to do. I listen when I have to. I have to say, I am aware of it okay. It is a fear, on some level. I don't want any self-professed prophecy happening here, so I avoid thinking [about it] because I had it once, so I am prone to that and, of course, I smoke.*

It should be noted that all of the women who participated in this research talked about the importance of health education and its role in the prevention of cervical cancer. However, each also stated that it is incumbent upon women to understand that no matter their decisions regarding cervical cancer treatment and the paths that they choose to follow regarding treatment, it is a woman's own sense of herself and the ability to trust in her own decisions that makes the biggest difference to her continuing good health. Agnes exemplified how a sense of oneself and trust in oneself are significant during a cervical cancer illness experience when she stated:

> *When I hear that another woman has this kind of cancer, it makes me want to inform them. The biggest thing I want to say to her is, it's up to you. Whatever path you choose get informed. Know your body. Know who you are. Inside and out. Have faith in yourself that you're going to make the right decision. Whatever decision it is that you make, know that it's the right decision.*

Although a dearth of research on health education in cancer care is available to heath services and delivery, it was clear in my work with these women that they remained sceptical regarding the information that they had received. Fear and mistrust of health education and service delivery again played a central role in what the women chose to accept as true or important. In short, providing women who are experiencing this illness the opportunity to ask and have their questions answered in relation to treatments and procedures would likely have spared these women much of the fear and frustration that was reported. However, meeting the particular needs of Aboriginal women, in these instances, requires specialized knowledge and information in order to develop health education and service delivery that they will actively seek and access. Given the current climate that health care professionals and health educators are now expected to deliver their services from within, the nature and quality of the information that they have available to provide to health consumers becomes ever more crucial.

### *The role of sexual activity in cervical cancer disease and illness*

All of the women reported that their views on sexual activity had changed after learning of their diagnosis. One of the participants reported that she continued to practice sexual activity strictly with the use of condoms. One factor that seemed to intensify their change in attitudes towards sexual activity and the incidence of cervical cancer was the information that became available on the sexually transmitted disease HPV and its reported role in the development of cervical cancer.

Referred to several times throughout this document, the newly available vaccine, Gardasil, was an important topic of concern among all of the women that I encountered during this study. Prevalent throughout our discussions was an apparent lack of understanding and/or confusion with regards to the incidence of HPV and how this may contribute to the development of cervical cancer. During my own learning on HPV and its potential role in the incidence of cervical cancer, I began to sense that current education and information were, at least, partly responsible for this confusion. For example, during a presentation at the *2008 Cancer Care Symposium* (Steed, 2008) in Edmonton, Alberta it was stated, “Because HPV is now so common, we no longer consider it to be a sexually transmitted infection”. This statement, coupled with the public health education and information that I had been exposed to in relation to the vaccine Gardasil, posed several questions.

First, upon realizing that HPV is indeed considered a sexually transmitted infection (STI), was the apparent lack of understanding and confusion regarding this vaccine being fully addressed by the current public health education and information? Second, and in the absence of clearly understood information, were ethical questions regarding the appropriateness of this vaccine for young girls being addressed by the health community? Third, given that a Canada-wide vaccination schedule had been planned to deliver this vaccine within the school systems across Canada to females between the ages of 10-12, was there hesitation on the part of the medical community to openly broach the topic of HPV as an STI? Finally, in light of the current research that deems Aboriginal women to be at the greatest risk for the development of cervical cancer, could the availability of this vaccine and HPV screening further perpetuate the view that these women are uniformed, misinformed, and/or neglectful of their sexual health? Although it was not the aim of this research to provide answers to these questions, what I did learn and experience first-hand was that the current approaches in health education and information delivery, in relation to HPV and the development of cervical cancer, worked to reinforce the fears and mistrust already held by these Aboriginal women and communities.

## *The role of Aboriginal traditional medicine in cancer treatment and care*

Traditional medicine was the final treatment that two of the five women had opted to access and their reports described a cure or healing of the cancer. An important part of this treatment for both women involved a faith in the ability of the medicine to provide a cure. Although Agnes stated that her faith in her decision was of equal importance to her choice of treatment, she also talked about belief and faith as contributing to the potential power of traditional medicine.

The source of the traditional medicine was not known to either of these participants although they both reported that it was a herbal mixture taken in the form of a tea for a specific period of time. On both occasions, these women had been told by the healers that each was no longer sick and within months of the treatment they both returned to a registered physician for verification. However, these same women, similar to all of the women who shared their stories in this research talked about their decisions regarding choice of treatment in terms of what western medicine reports to them.

The undermining of traditional medicine at this stage is likely subtle as health care consumers are taught that expedient diagnosis and treatment are the keys to curing and living after cancer. What does this ultimately mean for Aboriginal peoples who inherently possess the right to access both systems of knowledge? Is there clear access to both systems when one system of knowledge is so clearly placed in subjection to the other? And do Aboriginal peoples have the opportunity to access these rights? Although the answers to these questions are beyond the scope of this relatively small project, it is important to note that Aboriginal traditional medicine as a viable source of treatment for cancers is neither openly discussed nor viewed as the treatment of choice. Whether this is because of oppressive attitudes on the part of western health care or because it is too holy from Aboriginal perspectives to discuss in this arena, there is substantive evidence within this work and the work of other Indigenous scholars and researchers to suggest the need to explore the value and validity of Aboriginal traditional medicine as alternative or adjunct to western treatment regimens for cancer illness.

### *Traditional lifestyles and practices in the prevention of cervical cancer*

Similar to the research findings of Roberts (2005) in which the Woodland Cree of Northern Saskatchewan involved in her study describe their traditional views of health and wellness as encompassing much more than one's physical abilities and capacities, the women who participated in this research did not focus on the physical aspects of their illness experiences. Further, concepts such as balance, faith, and mental power were most often used when these women talked about their emotions and/or mental state during cervical cancer diagnoses and treatments.

As discussed in further detail in Chapter 6, adhering to a traditional lifestyle and participating in traditional or cultural practices was viewed by the women involved in this research as key to healthful living and well being. Part of what I learned was that the women's cervical cancer experiences in relation to the common treatments and procedures that they had undergone and the feelings of pain, fear, and frustration that these had induced were intimately tied to the disregard that they felt was shown for their femaleness. Support for this statement is suggested through the recognition that experiencing this illness during pregnancy worked to intensify the fear and frustration that was felt during the ordeal.

## *Chapter Summary*

The purpose of triangulation is to obtain confirmation of findings through a convergence of different perspectives (Goudreau, 2006). The triangulation for this research occurred in several distinct ways. First, narratives were developed from the transcripts of the women's interviews and returned to them for agreement and clarifications. At that time, the women were free to change, add, or delete any portion of the narrative. The women who returned their narratives did not request any changes. This form of member checking was completed with all, but one of the women. Second, some of the data was shown to support similar research on Aboriginal women's health and Indigenous women in relation to cervical cancer experience. In this way, the data of this research built on previous research in the areas of Aboriginal women's health and wellness. Third, conversations and a collaborative data session with cohorts, including Aboriginal research students, Aboriginal researchers, and Aboriginal women were shown to support some of the findings of this research. This was particularly the case for findings related to the Cree data with the women Elders, a lack of understanding related to the HPV vaccine regarding its potential to prevent cervical cancer, and the willingness of service providers to give women accurate information or the lack of information given to women by service providers in the following areas: the development of cervical cancer; the related diagnoses and treatments of cervical cancer; and the impacts of sexual activity and STI's on the development of cervical cancer. Suffice it to say, that many health service providers likely do not have a clear understanding of many of these issues themselves.

In addition, triangulation of this data will be shown through identifying how the work with the women Elders built on the findings of the work with the women. In this important way, this research demonstrated that health research with Aboriginal women that intends to articulate the significance of culture in relation to the health and wellness of Cree and Cree-Métis peoples is likely incomplete or may lack accurate understandings without the collaboration of traditional teachers and knowledge holders of communities. This triangulation and collaboration of findings is discussed in the following chapters.

In summary of this chapter, even though my mission during the interviews was to talk with these women about their cervical cancer experiences, past work in this area had taught me that speaking with Aboriginal women on issues that are private in nature is more easily and comfortably approached from within a context of women's overall health. Hence, the reasons I chose the questions asked and the approach towards the specific topic of concern. As well, the natural evolution of our relationships by this time were such that the women wanted me to have a full understanding or complete picture of their experiences and they were willing to share very intimate details of their lives. Again, without the development of these relationships in this way, it is very doubtful that the data would be as rich and meaningful as I found it.

Further, drawing meaning from the cervical cancer experiences of Cree and Cree-Métis women for other Aboriginal women may only be significant in terms of how Aboriginal women may use and benefit from what was learnt. This was clearly pointed out to me during a conversation with Dr. Cora Weber-Pillwax regarding the relationships that existed between the work with the women Elders and the experiences or stories of the women. Cora stated, "Do not ignore the present world. We live in it"[22] .

As I looked at each of the women's stories in order to discover what they each saw as important or significant regarding their experiences of cervical cancer, I found that they each only spoke about the cancer in a context of their overall health and wellness. No matter the stage at which they were diagnosed or the number of times that they were each diagnosed, the experience of cervical cancer was discussed as being one event in their lives that affected their overall health. What these women talked about over and over again, as affecting and changing their lives, I came to view as falling under four areas of priority in relation to their health and wellness. These areas of priority, as discussed in the following chapter, emerged as shared characteristics or qualities that were evident within each of the women's stories.

# CHAPTER SIX: CREE & CREE-MÉTIS WOMEN'S AREAS OF PRIORITIES REGARDING A SEXUAL HEALTH ILLNESS EXPERIENCE

Van Manen (1997) defines hermeneutic interpretation as the "the ability to be reflective, insightful, sensitive to language, and constantly open to experience" (Preface xi). Indigenous scholar Meyer (2003) states that Indigenous research, due to its intentions, processes, and outcomes, necessarily reflects a distinct hermeneutic interpretation. She states that "[E]ven at this beginning stage, our data will differ because we experience the world differently. And, "[W]e must get on with the wholeness we believe in, and this must reflect in our work, our writing, our deepest dreams" (Meyer, 2003, p. 250/251).

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[22] Personal Communication – Cora Weber-Pillwax. January 27, 2008. Calling Lake, AB.

The analyses and findings of this research, through Indigenous hermeneutic interpretation, based in the realities of Cree and Cree-Métis lived experience reflect the unique ways in which these women viewed their health and illness. From the stories and voices of these women emerged the inter-relationships between body, mind, and spirit as the 'meaning dimensions' that gave this data its distinct qualities. Drawn from the women's experiences, the areas of priority that these women identified in talking about their health and wellness are as follows:

1) Mental, emotional, and spiritual health are as significant as physical health;
2) Personal experience with sexual abuse and violence affects their sexual health;
3) The loss of cultural knowledge, in particular the loss of language, has overall affects on their health and wellness; and,
4) Traditional teachings and knowledge impact how these women care for themselves.

Throughout the text that reveals the areas of priority of these women, it was apparent that health and healing are viewed as inseparable or synonymous aspects of their wellness. These findings, by themselves, are nothing new in terms of the volumes of research that is available on Aboriginal women, their communities, and their health (Bennett, 2005; Goudreau, 2006; Roberts, 2005). Their further significance is realised as they provide evidence of what Aboriginal people continue to say in terms of their health and wellness: paths or approaches to the health and wellness of Aboriginal peoples must be holistic in nature while being inclusive of Aboriginal world views, Aboriginal teachings and knowledge, and elements that address healing from historical trauma and loss of language and culture. No matter the illness or issue at hand. The four areas of priority that emerged from the stories of these Cree and Cree-Métis women are discussed in this context and I begin by examining their experiences in relation to the significance that they place on mental, emotional, and spiritual health.

### *Mental, Emotional, & Spiritual Dimensions of Aboriginal Women's Health*

At times while I visited and spoke with the women who participated in this research, I found myself overwhelmed by many of the stories that they had shared. But, I was always in awe at the resiliency of these women as they talked about the tragedies that they had lived through and were sometimes continuing to experience. Remaining open to what they were teaching me required taking time to digest each experience, to reflect on each individual woman's experiences, and to care for my own personal health and wellness. What I was doing, in effect, was striving to maintain a balance within myself – within my own mental, emotional, and spiritual well being. I can say this about myself because I found the most useful and beneficial way in which to deal with the overwhelming aspects of these women's stories was to participate in activities that fed those dimensions of myself, such as talking with the Elders and participating in the sweat lodge ceremony.

What these women allude to, as revealed through their stories and experiences, is that in striving to maintain a balance in their own lives, they have come to understand that nurturing the mental, emotional, and spiritual aspects of themselves is just as significant to their well being as physical strength and vigour. Mental and spiritual dimensions were seen as integral to the health and healing of these women. In this section, I present the words and stories of the women that are shown to reflect this.

As the women talked about their experiences with cervical cancer, they often mentioned that this was only one illness or incident that had affected their health and wellness. Further, the physical part of the illnesses that they have experienced is not what they focused on during our discussions. Mental and emotional well being were most often referred to as having significant impacts on their health and wellness. As well, the women all spoke about their spirituality and spiritual wellness in relation to their overall health and wellness. This is similar to the findings of the majority of research and literature on Aboriginal peoples and their health. However, what I learnt from these women as they talked about nurturing their mental, emotional, and spiritual health is that the greatest impacts of illness in relation to sexual health are often experienced within these dimensions of oneself. Therefore, the women often placed the greater priority on these aspects of their health and healing.

In relation to the women's experiences with cervical cancer as only one incident to affect their health, several of the women reported having experienced multiple illnesses. For example, Debora talked about a chronic illness that she has had to endure in the following excerpt:

> *Predominant in my life is rheumatoid arthritis, which has been the deciding factor in how I've had to retrain and educate. I use to be a fitness instructor so I was fit and I did body weights. I was a high energy person. I did everything and I had to do it the best.*

Madelaine also talked about the many illnesses that she has experienced. She explained,

> *I'm 54. My mother passed away when she was 53, so that was a milestone cause they all died young so far, except for 1 aunt. I had my tonsils removed and my appendix removed and then the hysterectomy, then a couple of years later a red hot gallbladder, a bladder repair, 2 heart attacks, and heart surgery. Considering how much more illnesses I have than they did, [I'm doing good].*

One of the more significant factors identified by these women as affecting their health and wellness was stress. This was most often talked about as a response to the health and wellness concerns of family and family members. For example, Agnes had several members of her family who have been affected by cancer and other illnesses. Her own daughter had been diagnosed and treated for cancer and she had lost her father to cancer. Agnes talked about how these experiences have been a major source of anxiety and stress in her life when she explained,

> *I think that's all part of my health problems now. The depression and stress because we lived with it for so many months. I wasn't working and from the time my dad went into the hospital until he died. I was there almost every other day to help out with my mom and whether you're there or not, you're still carrying it around with you.*

Agnes referred to the affects of her father's illness on her own health. She talked about it as something that she "carried" on her person throughout the experience. In reflecting on her father's death and illness, Agnes noted that the impacts were much more than just physical. She stated,

> *What's really funny is that we buried my dad and it was two weeks later I got sick. I know a part of it, it's here [in my head]. It's mental and emotional, but then it's also physical.*

Marla also talked about 'carrying' the emotional and mental affects of illness around with her. She explained,

> *When I'm sick I'm carrying guilt around about being sick. So I fight to get better with my mind with praying, the cleansing, taking my different herbs, so that I don't get sick.*

Emotional well being also played a significant role in the lives of these women and may be attributed to, at least in part, the realization that the majority of the women had experienced physical, sexual, and verbal abuse. Marie spoke candidly about her life and what she has had to endure. She placed the most significant affects of these hardships on her emotional well being when she explained,

> *After being in an abusive relationship and having to give up my son to his dad for a while, I couldn't get [it] together cause he had cheated on me and he just again*

> *drained me of all my confidence that I had before I met him and I mean literally and emotionally. The verbal abuse was just, he could beat the shit out of me endless times and that goes away, but that emotional and that verbal [abuse] doesn't and you never forget.*

Marie also talked about emotional well being in relation to her cervical cancer experience. She referred to the emotional impacts of her cancer illness as being the part of the experience that will remain with her. Marie explained,

> *Because I've been affected by it myself, it will always be a part of my life. If it was just physical, I'd forget about it. But it's emotional. That's the part that I'll keep, but the physical I'll get rid of...the physical part is healed, the emotional part, any of that you don't forget.*

Madelaine also spoke of abuse that she had endured and of the severe impacts on her emotional and mental health. For many years of her young life, Madelaine explained, she was not really living, but simply existing. She stated,

> *I didn't even know who I was. I was just like a battered woman mentally emotionally. I just existed.*

In light of the hardships that these women had experienced, they often referred to their mental, emotional, and spiritual well being as critical to the outcomes of the situations. In this way, the women talked about mental health, emotional health, and spiritual health as dimensions of themselves. This was illustrated by the way in which the women all spoke of the mind as playing an essential role in their health and wellness. For example, Debora referred to her mind as one dimension of herself that plays a significant role in her health and wellness. She talked about the mind as being that part of herself that has its own outlook. Debora explained,

> *I was sick twice winter because I'm just not a healthy person. I want to be, my mind wants to be. This mind of mine does not equate with 58. It just doesn't. I feel like I did when I was 40 and my body doesn't do all the things that I want it to anymore. I just have to be respectful of it.*

All of the women talked about the importance of nurturing these dimensions of themselves. This was seen as being the most crucial part of their abilities to cope and live through their experiences. For instance Debora stated,

> *Attitude really does determine your aptitude. It's your attitude that determines your aptitude. There's so much power in that and that's where I get my power. All of it. I do a lot of self-care, my self-care. I have those Native flutes and this is my haven. Since I've gotten heart whole again, I have a strength inside that is just like I'm free. I really am free to make choices and I make choices based on what's healthy for me now.*

Marla referred to the measures she found to be valuable and effective in ensuring she remain healthy and well. She placed the most significance on her mind and her spirituality.

> *When I do get sick, it takes a lot of my spirituality, my mind to bring me back and nobody else can do that. I've got to be by myself.*

In talking about her mind and spirituality as important to her health and wellness, Marla most often attributed getting well to her connections with the mental and spiritual parts of herself. Marla explained further,

> *When I do get sick, I rely more on the mental and I'm listening to my body more. I'll ask for answers for what I need. I'm just more in tune psychologically of what I need to do. And a lot of times when I ask for the guidance of what to do then the*

> *answers will come to go get what I need. So that's what I do, but when you're really sick like that, your mind goes to a different dimension. You're on a different level.*

Madelaine, who has experienced multiple illnesses, also spoke about the spiritual and mental dimensions of herself and the role that this has played in her health and wellness. She explained,

> *Considering how much more illnesses I have than they did, [I'm doing good]. But I say it's my spirit. And I think that's another reason why I'm so [doing well] because I've been told since I was very young that I had a lot of patience. [For me to be healthy], its mentally. That's it. My physical body may not be that of a 16year old, but mentally, that's how I feel. It bothers me sometimes that I can't do things because my mind is always racing ahead of myself.*

Meyer (2003) talks about spirituality as the "starting point in which to engage in the multifaceted experience of our specific Indigenous epistemology" (p. 251). What these women reflect in these descriptions of their lived experience is that they understand their well being to include dimensions of the mind, body, and spirit. Marla further demonstrated her understanding of the connections between the body and the mind in speaking about her grandfather's death and illness when she explained,

> *[Looking at pictures]. No that's my grandfather. He lost his wife and he told me that he gave up. He finally came to the point that he wouldn't recognize her pictures. He gave up after his wife died. I think that was the big killer of him when she died. I couldn't believe it. He was 84. This was only about a year or 2 after she died. He just gave up after that. He told me, he said I'm going to die now. And he told me that my body's too strong so he got Alzheimer's.*

The ways in which these women approached illness and care for themselves was shown to be grounded in their understandings of the connections or interrelationships among mind, body, and spirit. For instance, Madelaine talked about reflecting on her feelings as having the greatest impact on her health and wellness. She stated,

> *I do a lot of writing and that has helped more than anything else cause I write down my feelings, like how I'm doing. It's not even journaling. I'm writing down poetry and I've had some of it published. I did that for Native services. They wanted me to describe how I was feeling at that particular time. I even published one of my poems in the newsletter that they had.*

Further, Marla talked about the role of the mind and prayer and the treatment she received from her grandfather for cervical cancer. She referred to the 'mental power' of knowing in relation to health and healing. Marla stated,

> *At that time, I didn't know what the treatment was but I knew that it included shells. [My grandfather] kept his medicine very, very private, very secret. It was herbs and it was the praying. It was the mental power because that's a big percentage of it. The mental power of knowing this is your cure. Knowing what it's going to do for you.*

Agnes also referred to the mental power of knowing that her decisions were correct. She was adamant that 'knowing what it's going to do for you' is key to health and healing no matter the issue. She stated,

> *When I went into the sweat lodge everything became clear. ...everything for me came down to me.... It was being aware of who I was in that particular moment and the strength that I gained.*

Marla also spoke about the health of the mind as being synonymous to the health of the body. She explained,

> *The way I was taught was mind over matter. Cleansing through your mind. It's telling your body to fight it off. Whatever ails you. A healthy mind is a healthy body.*

For Marla, this view of her mind and body as being separate but entwined dimensions of herself was reflected in the ways she cared for her health and wellness. She stated,

> *I bath and I shower. I meditate about how I'm going to do this. I pray for the answers to know how I'm going to get better and I rest and I try and eat well if I can. Depending on how sick I am, I'll just pray and try and dream about what I need to do to get myself better and then if I can't, of course, I'll go see the doctor to try and determine what to do.*

Marla talked about how she drew upon the dimensions of her body, mind, and spirit in caring for her health and wellness. She also saw seeking medical advice as an avenue to care for health and wellness, but placed the most significance on how her body, mind, and spirit acted together. This ability to integrate best practices from both the western and traditional world is referred to in the work of Roberts (2005) that studied the experiences of cancer among the Woodland Cree of Northern Saskatchewan. She states, "In fact, the health paradigm was shown to be a complex integration of Woodland Cree and Western medical health belief systems. The integration of both world views is so interwoven that it would be difficult to separate them" (Roberts, 2005, p. 124). Further, Roberts (2005) finds that the significance of this for Aboriginal peoples in experiencing cancer is related to the ability to "in essence creat[e] their own bridges between both knowledge systems" (p. 132).

The mental, emotional, and spiritual aspects of our selves and the role that they play in health and wellness are not foreign to non-Aboriginal peoples. Nor is it unexplored in health research and literature. What these women identified, throughout their stories, is that they are all aware of these parts or dimensions of themselves and how these have significant impacts on their health and wellness. Marla exemplified this when she stated, "I'm just more in tune psychologically of what I need to do". Further, the significant role that fear, anxiety, and mistrust have been shown to have on the experiences of these women and their health and wellness should emphasize the need for health systems and delivery to address mental, emotional, and spiritual aspects of care with Aboriginal women.

Within Aboriginal philosophies of health and wellness, balance across the dimensions of a person is key to health and wellness (Anderson, 2000; Goudreau, 2006; Loppie, 2004; Roberts, 2005). That these women have struggled to achieve some balance in their lives despite hardships and horrible lived experiences is a testament to their resiliency. What we learn from these women and their experiences is that treating physical ailments without addressing emotional, mental, and spiritual needs is grossly inadequate. This is true especially in light of the significance that these women placed on those dimensions of themselves as being crucial to their health and wellness. I now turn to the next area of priority that these women identified as having important impacts on their health and daily living – the impacts of abuse and violence.

### *Living with Abuse & Violence in the Historical Present*

> *The majority of Native girls during the residential school era had to pass through puberty in these institutions. Ceremonies around menstruation were replaced with, at best, no recognition of this passage. Cree Elder Kathleen Green recalls being terrified when her first menstruation appeared. Green was a residential school student at the time and thought she was dying until some older girls explained what was happening. (Anderson, 2000, p. 75)*

Historical trauma in relation to Aboriginal women was referred to in chapter one. Within the sections on the legacy of marginalization and variation in the social environment, I cited that some of the affects of historical trauma for Aboriginal women include higher rates of spousal abuse, higher rates of sexual abuse and exploitation, higher rates of victimization, experiencing more severe forms of violence, and the excessive and invasive applications of child welfare in the lives of Aboriginal mothers (Bennett, 2005). These forms of abuse and violence were also found to be prevalent in the lives of these Cree and Cree-Métis women and represent one area that they identified as a priority in relation to their health and wellness.

Anderson (2000) talks about how a "radical shift in values opened up the conditions for the epidemic proportions of violence against women in Aboriginal communities" (p. 91). The shift from traditional views of women as sacred in relation to their abilities to have children represents just one area of significant change for Aboriginal women (Anderson, 2000; Loppie, 2004). The stories of these Cree and Cree-Métis women reveal that they have experienced several forms of abuse and violence. In fact, only one woman did not report that she had experienced sexual abuse throughout her lifespan. One of the women reported that her grandmother had been raped by her own father at the age of 14 and subsequently became pregnant. Another participant talked about sexual abuse during her life when she revealed,

> *My aunt I don't know much about because she had been married to a very abusive man and we didn't have contact with her. If you said anything to her, she didn't want hear it. Her husband was abusive and he tried to rape me. Years later he told her and she ended up going back to him even though he did admit it to her.*

One of the women also talked about experiencing sexual abuse in relation to the medical attention that she received as a child when she explained,

> *He was our doctor since we were kids and he used to pat me on the bum and say if you ever need to talk, then I'll meet you somewhere. That just turned me right off. [I thought] I don't think so and he's saying, I get a little flustered when I see a*

> *girl with her pants down. [Since then] I don't have a gynaecologist, just a regular doctor. I just don't feel comfortable around doctors anymore....*

Another participant talked about sexual abuse that happened to one of her children. She explained that some of the more devastating and lasting impacts of this experience on her child were related to self-esteem. She stated,

> *So I asked [my child], what do you want to do? What do you want to do? Here are your options. It was all about power, I don't know how I knew that and I said to [my child] you have to get that back and you have to do it this way or this way or this way. And we called the police. And then child welfare of course and we had counselling. We both did one on one counselling. My [child] for over a year and I had it for a year. [My child] still goes through cycles where they have to go through more layers and more layers because it certainly had an effect on [my child]. On [my child's] sexuality, even today. [The child] has so much talent and ability and yet there's [the child's] self esteem.*

Violence in the lives of these women was also revealed. Similar to what Dion Stout and Kipling (1999) find, these forms of abuse were often perpetrated on these women for periods of time that spanned several decades. For example, one participant explained that she endured physical and emotional abuse throughout most of her young life. She stated,

> *It was a while ago too, and top of that I didn't even know who I was. I was just like a battered woman mentally, emotionally and I just existed.... Well back then I was like a little robot. I guess I just functioned. I was kind of just going along. I was like that from a young age and I didn't know emotions.*

Several of the women also talked about the government and its social service departments as having had an impact on their experiences. One participant spoke about the persistent forms of coercion that she had experienced in saying,

> *I felt like [I was being] pushed by the government cause I was on social assistance by then. My second child, they tried to convince me to give him up because by then I was 20. This social worker kept coming to see me and saying that there's nothing wrong with going to see a psychiatrist to find out why you're pregnant again. And I said I know why.*

In talking about their experiences, these Cree and Cree-Métis women often referred to feelings of isolation. One participant expressed feelings of isolation in relation to being physically abused at the hands of a partner when she stated,

> *...I was like a little robot. I guess I just functioned. I was kind of just going along. I was like that from a young age and I didn't know emotions.*

Isolation and feelings of isolation, as a result of sexual abuse and violence, are referred to in research that talks about historical trauma among Aboriginal peoples. Perhaps of note, within this research, is that feelings of isolation may have contributed to some of the women's beliefs that there was nowhere or no one to turn to in relation to cervical cancer. One participant spoke to this issue in saying,

> *I don't [talk to anyone about it]. There's no one really that I can unless I go to a doctor. It's not like you can go into the doctor's now and say I'd like to have a discussion with you. Do you have half an hour? Who do you talk to about it really.... It may come back. It may not. So pretty much, there is no one to talk to, there really isn't.*

Roberts (2005), also talks about the occurrence of isolation in relation to the cancer experiences of the Woodland Cree. She states, "[C]rying and social isolation was a common emotional response" (Roberts, 2005, p. 127). What the stories of these women may further reveal is that their experiences with sexual abuse and violence may have contributed to and perhaps exacerbated the feelings of isolation around cervical cancer. Many of the women's experiences with sexual abuse and violence were also the experiences of their mothers and grandmothers. These experiences often led to a severe lack of information and knowledge in relation to female sexual and reproductive health. One of the participants referred to the impacts of this on her knowledge and understanding of sexual and reproductive health as a child and young woman. She stated,

> *But as far as the personal parts go. The ovaries and the cervix and the vagina and all that stuff, it's not something that anybody would ever teach you unless you ask. And at the same time, like I said my grandmother always said, it's dirty. If you ever asked her anything like that, it's off limits. Absolutely and then years later I understood why, because she was molested as a child and got pregnant by her father in [the 1920's] at 14 years old.*

A lack of knowledge and understanding in relation to menstruation was discussed by several of the women. One participant stated,

> *I remember that day [when I first started menstruating]. Our pastor came and...he offered to take all of us to the exposition. I was about 10 or 11. So he brought us home that day and I wanted to change my clothes. I...pulled my shorts down and I went oh! My sister did the same thing. She was 13 and saw the blood and said, 'I want a band aid. I want a band aid'.*

The participants felt that this lack of knowledge and understanding regarding female sexual and reproductive health contributed to their experiences of ill sexual health, including the development of cervical cancer. She stated,

> *[There wasn't anything I could do earlier to prevent the disease] because I didn't have any knowledge. And I didn't feel anything. As a kid not knowing any better, I wasn't taught about sex and to be careful. I wasn't taught anything, just that it was dirty, dirty, dirty, and so I had to go out and learn on my own unfortunately.*

In talking about their experiences with sexual abuse and violence, several of the women acknowledged that trauma in the lives of their mothers and grandmothers, particularly in relation to residential schooling, led to the occurrence of these incidents during their own lifetimes. Anderson (2000) talks about residential schooling and its impacts on the sexual health of Aboriginal women. She states that the arrival of the Church and its doctrines, such as the "shame based interpretation of menstruation", were key to the 'spiritual dislocation' of Aboriginal women leading to radical changes in the ways that Native women were viewed and treated (Anderson, 2000, p. 77). The experiences of these women reveal that sexual abuse and violence continued to have severe and lingering impacts on their health and wellness.

The complex nature and effects of this abuse are reflected in the words and experiences of these women and as such demand further understanding in relation to sexual health and wellness. Moreover, achieving personal sexual health and wellness likely requires healing from the effects of these experiences. One participant exemplified this when she stated,

> *Our time that we have here together is so short. Quit keeping secrets. The secrets that we keep. Everything. Everything. People are starting to come out now and talk about the sexual abuse that they endured through the church for example, and its healing people. A lot of the Elders are starting to talk about it and some people think it's a bad thing. They think if you're talking about the past, it's the past. But I think there are some strong words and in order for us to be healthy we have to go back. You have to know who you are as a people and get rid of all those demons.*

Throughout this section, I have discussed the impacts of sexual abuse and violence as elements of historical trauma. However, along with other Aboriginal people, I also acknowledge that the sexual abuse and violence that many Aboriginal women have experienced and continue to experience are much more than the impacts or effects of historical trauma. In regards to trauma in the lives of Aboriginal peoples, Elder Marg Cardinal stated, "[W]e do not accept that the trauma that is happening today is an effect. It's not an effect – it's happening"[23]. The stories and experiences of these Cree and Cree-Métis women were shown to reveal that this also has been the case in their lives. Additionally, the loss of cultural teachings and knowledge on the health and wellness of Aboriginal peoples have been suggested to have important impacts on the health and wellness of Aboriginal women. The loss of cultural teachings and knowledge is discussed as the next area of priority that was identified by these Cree and Cree-Métis female participants as having significant impacts on their health and wellness.

### *The Loss of Culture & Language*

> *The dirty, easy squaw was invented long before poverty, abuse and oppression beset our peoples. She was invented and then reinforced because she proved useful to the colonizer. The 'uncivilized' squaw justified taking over Indian land. She eased the conscience of those who wished to sexually abuse without consequence. She was handy to greedy consumers. Dirty and lazy, she excused those who removed her children and paved the way for assimilation into mainstream culture. She allowed for the righteous position of those who participated in the eradication of Native culture, language and tradition. (Anderson, 2000, p. 100)*

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[23] Personal Communication – Elder Marg Cardinal. March, 2007. A Mental Health Gathering for Communities Interested in Mental Health Research: A Joint Collaboration between the Alberta ACADRE Network, CURA Healing Through Language and Culture, and Aboriginal communities.

Although she was only 32 at the time of the interview, Marla talked about her lived experiences in ways that revealed a deep sense of connection to her Aboriginality. During a later conversation, I mentioned that several areas of priority for the women seemed to be emerging from the stories. Marla then stated, that the first thing she thought of, when I mentioned areas of priority in the lives of Cree and Cree-Métis women was her own sense of loss in relation to her culture and language. For Marla, this was intimately tied to the loss of her grandfather a few years earlier. With Marla's permission, I retell that part of our conversation here.

> *Marla: That's the first thing that came to my mind when you started talking about the women. I feel like I've lost that this past little while. I've lost some of the words. I can't remember them all. And being able to connect to that sense of myself. But it comes back to you. I learnt that the hard way three years ago when my grandfather passed away. Now he comes back to me in my dreams. He's still there. His words come back to me too when I need them. He used to say to me, 'Marla. You're good'. I remember that now when I need it. There was so much teaching in his words. And in his actions. The way he treated my grandmother. When she got sick, he carried her from his house to the hospital. And he was 76. He used to say, 'I loved that woman'. But he showed us that. He taught us that right till the very end. And he went through so much.*
>
> *Angie: Was your grandfather in a residential school?*
>
> *Marla: No, but his children were. He grew up in the bush. His people were trappers and medicine people and that's how he grew up. But then he had to come in from the bush and so they told him he had TB. And they took his kids and put them all in a residential school. He never had it.*
>
> *Angie: He never had TB?*

> *Marla: No. They told him that so they could take his kids. I remember my dad told me that story. He was crying and he told me that he had to go and visit his dad through the glass. He could only touch him through the glass and they were all crying. Then they sent my dad to a residential school and he stayed there till he was ten when he lost his leg. And they never told my grandfather till a month after it happened. They were negligent. They never sent him to the hospital, so he lost his leg.*

During our conversation, Marla talked about the many losses that she and her family have experienced. Tied to the loss of her grandfather, one of the people that Marla identified throughout her story as having important impacts on her sense of herself as a Cree being was the frustration that she continued to feel about losing her language. For Marla, the loss of language translated into a loss of a sense of herself or identity. The relationship between Native language and identity are well established in research generally. Weber-Pillwax (2003) states in her work on identity formation and consciousness of the Cree and Métis peoples of Northern Alberta that many contemporary Indigenous persons, particularly the youth, struggle with identity since they are unable to find the words in the English language that "fit with how they are experiencing themselves to be" (p. 7). These comments are in keeping with the following statement by Elder Eric Cardinal, referring to the Cree language: "[L]anguage gives power to our culture and our beliefs"[24].

In terms of the health and wellness of Cree and Cree-Métis women, powerful impacts from the loss of one's Native language were suggested from all of the participants in this research. Madelaine talked about the loss of her Native language when she stated,

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[24] Personal Communication – Elder Eric Cardinal. March, 2007. A Mental Health Gathering for Communities Interested in Mental Health Research: A Joint Collaboration between the Alberta ACADRE Network, CURA Healing Through Language and Culture, and Aboriginal communities.

> *My mother was Métis. My father was too. They both spoke Cree and I don't know how to speak it to this day. She tried to teach me one time, but she said I sounded like a white man and she got frustrated. It was just that she didn't give me the chance to.*

Marie also stated,

> *Speaking Cree was the most important for me and I really wanted to learn it.*

The women also talked about the loss of cultural teachings and knowledge. Some of this loss was seen as a result of the mistrust that they sometimes held for their own traditions and teachings. For example, Marla talked about her own scepticism in relation to her grandfather's medicine. She explained,

> *I was always kind of a sceptic to my grandfather. My brother came home one day and he had an enlarged heart the doctors told him. He went to my grandfather to get doctored and when he went back to the doctors about two years later, they asked him if he had gotten a surgery or something. He said no, well I got no scars here and so he told them about my grandfather. They told him that he was full of it. They more or less told him that he was a liar. They told him he'd be lucky to live to be 30. This is my older brother who's 35 now.*

For contemporary Aboriginal peoples, this negative view on the part of western science towards the capabilities and value of traditional medicine and knowledge is nothing new. These negative views, on the part of Aboriginal peoples themselves, are seen by many Elders and community members to stem from state and church tactics to control and/or assimilate Aboriginal peoples (Letendre, 2002; Weber-Pillwax, 2003). One such tactic is fear. Marla referred to the use of such tactics in explaining that her scepticism was also related to western views of traditional Aboriginal medicine as skulduggery and witchcraft. She stated,

> *[My grandfather] said, you know what, you're going to be okay and at the same time I'm hearing from different doctors that they're sceptic about my grandfather. That they have heard about my grandfather's medicine and they think it's a joke. [Also] my own people, but they've been taught to think that too for whatever reasons.*

Marie also talked about the loss of cultural traditions and practices. She spoke of the place in which she learnt and practiced some of these traditions with fondness. Marie stated,

> *When grandpa was alive [they used to trap and fish], but after he passed away everything is sort of gone.... And we use to go the Canadian Native Friendship Centre. We learned how to make moss bags. We spent a lot of time there. Our Christmases were spent there. It was an old building. I think it's gone now. I loved that building.*

Each of the women spoke about the loss of cultural teachings and knowledge. Although the loss of language was always central to these discussions, they also spoke about the loss of cultural practices and traditions. Further, these cultural practices and traditions were largely viewed as a means to living a better life, a life in which one was valued. For instance, Madelaine talked about the differences between traditional marriage and marriage that was influenced by European ideals. She stated that her grandparents were married according to "the custom of the country[25]", rather than according to traditional Métis ideals that were based in independence (Van Kirk, 1980). Madelaine explained,

> *My grandparents were married more like a country couple, as opposed to a Métis couple. A kind of 'stand by your man theme', regardless of family violence, as opposed to independence and learning from your mistakes.*

Agnes also talked about the loss of cultural traditions and practices in relation to young Aboriginal women and the 'rites of passage'. She stated that these traditional teachings were a kind of 'welcoming' for a young girl who began her menstruation and that the experience was meant to be a loving one. Agnes explained,

> *The only woman I ever knew who was treated special when she started to menstruate was a friend. Through traditional teachings, she was welcomed by the other women when she began her 'moon time'. They stroked her hair. They cooked for her and bathed her. The other women all came to visit her. It sounded like a very loving experience.*

Although only one of the women had experienced a 'rites of passage' ceremony, they all talked about this practice in relation to Cree and Cree-Métis women's sexual health and wellness. Anderson (2000) states, "[T]raditional understandings of menstruation were central to the understanding of creative female energy, and the power that it carried" (p. 74). This view is in sharp contrast to the experiences of some of these women, in which their passage from a young girl to womanhood was a frightful and sometimes humiliating event. Tied to historical and societal impacts, such as residential schooling and the different forms of abuse perpetrated on Aboriginal children, the ways in which Aboriginal women are sometimes viewed is often demoralizing and self deprecating. What these women recognised as important to their own identities and sense of self worth, was that the loss of language, cultural teachings, and knowledge has had a negative impact on their lives. In terms of their own health and wellness, and the health and wellness of their families, cultural traditions and practices were seen as valuable tools that lead to positive outcomes, including a sense of self worth.

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[25] According to Van Kirk in "Many Tender Ties…" (1980), many European men traveled to what is now Northern Canada and practiced a form of marriage or living arrangement based on what became known as the 'custom of the country'. Many Aboriginal women were bound in unions similar to this. Upon the arrival of European women to Northern Canada, most of these women were abandoned by their 'country husband' and left on their own with 'half breed' children. Some would remain married to their 'county husbands' throughout their lives.

### *Traditional Teachings & Knowledge in Caring for Oneself*

> *Aboriginal traditions provide a way to express who we are with pride. Several women in the study talked about pride and identity. One said she feels proud taking care of and carrying a drum. Many women in this study identified themselves with the drum, and could not imagine their lives without it. The more we know about our sacred items, such as the drum, the more we will know about ourselves and how to obtain, and maintain, balance. (Goudreau, 2006)*

In talking with the women about their health and illness experiences, I found that they each referred to cultural practices and traditions as sources of knowledge that they drew upon in caring for themselves. Although this knowledge was usually not talked about in terms of specific cultural teachings, an examination of their health and illness experiences revealed positive influences and impacts of traditional teachings and knowledge on their health and wellness. These important influences and impacts are grounded in the cultural teachings and knowledge of Cree and Cree-Métis peoples and are articulated as characteristics of Indigenous peoples by Indigenous peoples themselves. I begin by talking about the ways in which these women describe health and illness experience.

Within the stories of these Cree and Cree-Métis women, the meanings of health and illness were often described in relation to the family. For example, Debora explained that her mental health was tied to the relationships that she held with her grandchildren when she stated,

> *My mental health is that I have four grandkids.... So I do okay. I do.*

Marie talked about her health and wellness as 'feeling good' through helping and supporting family members. She stated,

> *I use to go to my sister's house every Sunday and I'd clean her house for about four or five hours and then I'd cook her a really cool dinner and we'd have dinner together. That felt really good. That felt good cause we were supporting each other.*

Marie further explained the value that she placed on these relationships as an important source of her own support. She stated,

> *I think that [you need to] have a good support system as far as family goes. If they show you that they care about you when you're down and they're there. And they just pick you up and they say well you know shit happens. Just go. Keep going.*

In describing what was important to her healing, Agnes also identified relationships as significant. For Agnes, these relationships had enabled her to go through her cancer illness as part of a group experience. These relationships were extended to include aunts and women that she attended gatherings with. Agnes explained,

> *I talk to my aunts when I become ill and other cancer survivors. They're all out there. I attend these women's gatherings and by sitting around and talking we go through these things together.*

Aboriginal women, including the Cree and Cree-Métis, will tend to draw on family relationships and extended family relationships when they face health and illness issues. Goudreau (2006) references Castellano (2002) and the Royal Commission on Aboriginal Peoples (1996a) in explaining:

> *In the Aboriginal community, social support networks are built in the extended family structure. In an extended family, care and nurturing are distributed over a large network of grandparents, aunts, uncles, cousins, even extending traditionally to the clan system.... As noted in RCAP, 'inside the web of family, norms of sharing and mutual aid provided a social safety net for every individual'.... Under the patriarchal influences of the Western concept of the nuclear family, extended Aboriginal families were disrupted. However, the notion of extended family continues to be a powerful ideal etched deep in the psyche of Aboriginal people (p. 25).*

Agnes also talked about her illness experiences in relation to the illnesses of her family members when she explained:

> *[My father] got sick just after I had gotten over my shingles. Some people were saying, you got shingles cause your dad got sick. I'd say no? Back then my dad wasn't even sick, not that I knew of. I just knew that he was kind of going downhill. It was a slow progression.*

The meanings that these women gave health and illness experiences were embedded in their relationships with others and their relationships to other significant persons in their lives. This is consistent with Cree and Cree-Métis women's sense of themselves in relation to their roles as woman, mother, sister, auntie, and daughter. Agnes referred to the role of women as the centre of the family in talking about her experiences with cancer illness. She stated,

> *You either hit that wall and you pick yourself up or you never do. If you don't then there goes another generation. There goes her kids - because the women are the centre of the family. You can pick yourself up and show your kids what a strong independent person you can be. You're their lifeblood. You're their strength. You're everything. You're their power.*

In talking about the role of women as the centre of the family, Agnes used words like 'lifeblood', 'power', and 'strength' in relation to independence and responsibility. As a person with ancestral ties to the Métis people of Battoche and a deep knowledge of the history of the Riel Rebellion, it was not surprising that Agnes talked about her independence as a source of power and strength. For Agnes, responsibilities towards her family were met through fulfilling responsibilities towards herself. She stated,

> *In order for my family to be healthy and happy and my friends and my marriage, I have to be healthy and happy. That's my job.*

Madelaine associated the ways in which she raised her children with independence. For Madelaine, independence was also tied to traditional teachings and practices. She explained,

> *I think that there's a lot of the old ways in me and even with the ways that I raised my children and the ways that I interact with my granddaughter. I can see the differences in myself with being a single parent. That's different.*

Further, Madelaine revealed the central role that her own mother played in teaching modesty and humbleness. It is important to note that Madelaine's understandings of modesty and humbleness are positive reinforcements that do not include negative connotations, such as shame towards the female body. She stated,

> *My kids talk about their modesty. My son married the woman he has a daughter with and he couldn't get used to her being so open with her body. That's a traditional thing.... A lot of modesty was instilled in us. My mother instilled that in us. It's more than just that and I've been thinking about it. I don't know if shame is the right word with coming up in the residential school or the influence of the church. [What she taught us] didn't have all that other stuff mixed up in it.*

Although I touched on the topic of 'shame-based orientations' as introduced to Aboriginal peoples through church doctrines and residential schooling in the previous section, it is important to discuss this further in relation to the cultural teachings and knowledge that contemporary Cree and Cree-Métis women have available to them in valuing their bodies. The many degrading acts that were perpetrated against Aboriginal children attending residential schooling, in the name of Judeo-Christian culture, easily reflect these forms of "inspection" as damaging to a positive female self-image (Anderson, 2000, p. 75). Anderson (2000) recounts one story or description of these forms of inspection, as told by residential school survivor Nora Bernard. Anderson (2000) writes,

> *I don't know what Sister Wejuipsetamite'w's [the sniffer] problem was, for instance, she used to have us girls form a line and take the crotch of our panties and spread them on the palm of our hands as we all walked by her so she could see if they were dirty. She told us that she didn't want us going to church smelly but why didn't she have all of us take a bath or a shower before church?*[26] (p. 76)

The powerful images that these stories evoke within us are in stark contrast to the teachings and lessons that are found within many Cree and Cree-Métis cultural traditions and practices. Anderson (2000) reminds us of the positive reinforcements that are entrenched within traditional teachings and knowledge in relation to the sacredness of the female body and its capacities to sustain life. She explains,

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[26] This excerpt is taken from the work of Isabelle Knockwood (1992): Out of the Depths: The Experience of Míkmaw Children at the Indian Residential School at Shubenacadie, Nova Scotia, p. 92.

> *Aboriginal teens may not carry the same sense of shame around pregnancy that they once did, but there are still many who punish themselves (and are punished) through careless treatment or abuse of the body. Women might engage in unsafe or unwanted sex, eat poorly or abuse ourselves through dysfunctional eating patterns, alcohol abuse, smoking, or other things that are unhealthy for us. All of us, young and old, have work to do around remembering and reconstructing the sacredness of our bodies. One way we can do this is to think of the female body in relation to its life-giving ability (Anderson, 2000, p. 195).*

In her work, *A Recognition of Being: Reconstructing Native Womanhood*, Anderson (2000) talks about Aboriginal female role models as being traditionally strong and independent:

> *Strong, independent female role models provide Native girls with the sense that they can overcome whatever obstacles they will inevitably encounter. These lessons have traditionally been learned in a non-verbal way, by example, as in the case of Mohawk educator Marlene Brant Castellano. She remembers her mother's style of teaching:*
>
> > *Without ever letting us know, without being ambitious for us or pushing us, mother held onto the belief that she had it in her to 'be somebody.' If there were any obstacles she just barrelled them out of the way so that we could be whatever we wanted to be (p. 118).*

In the previous section, I quoted Marla as saying that her grandfather taught her important lessons regarding the belief that she could 'be somebody'. Marla explained later that she was also passing this important lesson on to her own daughter. In talking about the approach that she used to inform her daughter of the importance of safe sexual activity, Marla stated,

> *That's exactly how I've been doing it. That's what I've been doing and talking on the level of respect and the value in it and the value in yourself. And what you need for yourself, so you'll feel good.*

As I examined the women's stories, I noted that this strong sense of value for self worth and independence also emerged as the women explained how they viewed and cared for themselves in relation to illness experiences. For example, Madelaine stated,

> *I didn't know a lot of things and it wasn't until I was older that I started to fight back. The first thing that helped me to start making moves for myself was that I started to think that I was worthwhile... Twenty years ago I would have looked at [cervical cancer] as being a shameful thing. I've come full circle now.*

Marla also talked about independence in relation to experiencing an illness. For Marla, these statements revealed that she places value on what she has to offer others and that this is dependent on meeting the responsibilities or possessing the abilities to care for herself. Marla explained,

> *I never thought about being sick and the first thing I think is no independence. No independence and everybody having to take care of me when I've got so much to offer everybody else. So when I'm sick, I'm scared everybody else has to work harder. That's what I think. I think if I don't take care of myself then everybody has to take of me.*

All of these women identified relationships, independence, and self worth as elements of their health and wellness experiences. Their stories revealed that cultural teachings and knowledge provide much of the foundation for these views. Roberts (2005), in her research on cancer among the Northern Cree of Saskatchewan narrates how health is envisioned among the members of her community. She writes,

> *To be healthy for me is be able to work, be able to look after myself, be able to go out in the community and do stuff with people. For me to be healthy also relates to happiness, my goal is to be reasonably healthy and happy, and healthy to me also goes to quality of life, which also makes you happy. It means being physically fit, I mean I've changed so much mentally, you know, you have to be mentally fit and physically fit, I guess I'd have to say spiritually, mentally, all the four aspects (Roberts, 2005, p. 74).*

What I learned from the Cree and Cree-Métis women who participated in this research was that despite the many assaults on Aboriginal women's views and values of themselves, through historical trauma and incidents of sexual abuse and violence, these women have retained positive images of themselves. And the ways in which they achieved this were grounded in cultural teachings and knowledge that provided the descriptions or rules for the traditional constructs of the female role, self worth, and independence. Further, these traditional constructs of the female role, self worth, and independence are expressed through the relationships that these women held with others.

That these realisations are largely couched within the parameters of identity is apparent. In the final discussion on cultural teachings and knowledge as an area of priority of Cree and Cree-Métis women in relation to health and wellness, I look at how the stories of these Aboriginal women further revealed that positive identities were reinforced though cultural traditions and practices.

In exploring the connections between Aboriginal women's hand drumming and health promotion, Goudreau (2006) talked about the importance of cultural practices in relation to Aboriginal identity and health. She stated,

> *The Elders say we must know where we come from to know who we are. Identity determines how Aboriginal People view themselves (RCAP, Vol.4, 1996, p. 534). I*

> *noticed as I began learning about my culture that those who participated in cultural practices seemed to be most healthy (p.23).*

Throughout the women's stories, they each mentioned participation in some form of cultural activity. Although some of the activities were described in the past tense, the women acknowledged that these practices were important as part of their positive experiences as Cree and Cree-Métis women. In this way, these activities have been sources of positive reinforcement of the images that these women have of themselves as Cree and Cree-Métis women. For example, Agnes stated that she attended women's talking circles and that this was an important part of her self-care. Debora also talked about her use of Native flutes in this way. She stated,

> *I do a lot of self-care, my self-care. I have those Native flutes and this is my haven.*

Marie talked about hunting, trapping, and fishing as a child. She also stated that her fondest memories of her childhood were those that involved participation in cultural activities, such as attending pow wows and going to gatherings with her grandmother. Madelaine also talked about participating in cultural activities, such as beading and commented on her son's involvement in an Aboriginal organization. This was important to Madelaine's views on how her grandchildren would be raised. She stated,

> *It's important, these views of these big, strong Métis men and their boats. It's about pride in who you are and where you came from. Those are all good things to pass on to my granddaughter.*

Agnes spoke about participating in the cultural practice and ceremony known as the sweat lodge. She spoke about this event as being instrumental to her decision regarding the use of traditional medicine. Agnes explained,

> *It was the only decision I could make. When I went to a sweat lodge everything became clear. Everything. And it was also that everything for me came down to me. This is my body. Not the doctors'. Not the medicine men. It was being aware of who I was in that particular moment and the strength that I gained. That was probably one of the most enlightening times in my life. That day. It helped me through, because before that I was so scared and when I walked in I felt so calm.*

Agnes referred to her sense of identity when she talked about being aware of who she was and the strength that she gained from this. Marla talked about her sense of who she is as developing through the time spent with her grandparents. She explained,

> *You don't really know who you are until you spend time with your grandparents.... I just see my grandparents. Seeing how they were together and how they were partners through everything. Well for me, it was even my grandparents [who] always said be with one person and only be with that person.... This was being clean to yourself of not bringing other people into your relationship.*

Elder Frank Daniels spoke about the relationships among culture, strength, and healing. He stated, "[T]o heal is to get strong. Our culture is our strength. So when we gain our culture, we gain strength"[27]. In closing this chapter and reflecting upon what was learnt with these women and through their stories, I became more fully aware of the cyclical nature of coming to know as an Indigenous person and how this forms part of our uniqueness as Cree and Cree-Métis beings. The knowledge that has been made available to us through the wisdom and ways of our ancestors continues to provide the foundations for our health and wellness. Marla exemplified this in her following statements:

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[27] Personal Communication – Elder Frank Daniels. March, 2007. A Mental Health Gathering for Communities Interested in Mental Health Research: A Joint Collaboration between the Alberta ACADRE Network, CURA Healing Through Language and Culture, and Aboriginal communities.

> *It's all tied together. My grandma used to have a nap in the afternoon and relax and she'd say sit down don't do anything. You know more or less relax. When kokum was around she'd say rest and don't do anything, drink lots of water and we were always eating. Probably about four times a day we ate but then we worked hard.*

### *Chapter Summary*

In this chapter, I discussed the areas of priority that were revealed through examining the health and illness experiences of the Cree and Cree-Métis women who participated in this research. First, mental, emotional, and spiritual dimensions of health were discussed and shown to be as significant for these women as their physical health. This was reflected in the women's descriptions of health and illness experience and how they had identified that the greatest impacts on their wellness were from within these dimensions. Next, the women's personal experiences with sexual abuse and violence were shown to be an area of priority for these women as their effects and impacts on sexual health and wellness are isolating, lingering, and self-deprecating. It was also noted that while historical trauma was instrumental in introducing harmful and damaging views of Aboriginal women to society, many Aboriginal peoples continue to experience physical and mental abuse, sexual abuse, and exploitation. As well, the loss of cultural knowledge, in particular the loss of language, was identified as an area of priority of these women. This was shown to have negative and deleterious impacts on Cree and Cree-Métis/Aboriginal women's self-images and identities. In conclusion, traditional teachings and knowledge were discussed and identified as continuing to provide the foundations for a positive female Cree and Cree-Métis self-image and identity. Further, this was examined in relation to the ways in which cultural teachings and knowledge provide the descriptions or rules for the traditional constructs of the female role, self worth, and independence. The integral role of relationships in the expression of these traditional constructs was also established. In the next chapter, I talk about how the work with the women Elders was shown to validate the experiences of the women who shared their stories as Cree and Cree-Métis ways of life are shown to provide the strength and vitality for the health and wellness of these women.

# CHAPTER SEVEN: VALIDATING & BUILDING ON THE STORIES AND LIVED EXPERIENCES OF CREE & CREE-MÉTIS WOMEN

> *Statistics show the inroads of winter. Just as counting the dead plants is an inadequate measure of the life of the seeds, so counting the deaths, the alcoholism rates, the suicides, the murders, and the dropouts is inadequate to measure the vitality of Native life. (Hampton, 1995, p. 35)*

This chapter talks about the work with Elders Isabel Auger, Rita Auger, Marg Friedel, and Alice Reid, and how this was shown to validate and build upon the stories and lived experiences of Cree and Cree-Métis women. The chapter is presented in two parts. The first part talks about the processes that occurred in working with the women Elders. Within this section, I describe the roles of the Elders and myself as the researcher in the processes that would unfold. This includes how these roles would enable the principles of the research framework to be manifest in the research and how working with the women Elders would enable the triangulation of the findings from the data of the women. The second part of the chapter talks about what was learned from the women Elders in relation to the women's stories. Within this section, I reveal how the teachings and stories of the Elders would validate the experiences of the Cree and Cree-Métis women as integral to Cree and Cree-Métis women's health and wellness. In conclusion, I talk about the findings of this research as addressing the questions of the research in relation to understanding the ways in which Cree life were manifest in the lived experiences of these women.

### *Processes in Working With Women Elders*

As mentioned in chapter three, it was not until late in the research that I recognised my role as a facilitator in the processes that would unfold. In analysing the transcripts and my journaling in relation to the women Elders, I found that stepping away from the data in order to look at the processes that were unfolding was key to understanding the ways in which this work would build on the work with the women[28]. Although the data from the work with the women Elders was similar to the data from the work with the women in that cultural teachings and knowledge related to Cree and Cree-Métis women's health and wellness were identified, the processes through which the women Elders would work would also have significant impacts on what I would learn. In order to demonstrate the significance of these impacts, I begin by describing the different roles of the women Elders and myself, as the researcher, in these processes.

Prior to discussing what I learned in working with the women Elders, it is important for the reader to know that the analyses presented here with regards to the Elder's processes and teachings only reflects how I have come to understand them. While this can be said with regards to what I learned from the women as well, it is important to recognise that my intentions in speaking about Elders and their cultural teachings and knowledge is not meant to talk about how they see and understand the knowledge that was discussed. As well, it should be noted that specific cultural teachings and knowledge related to illness treatments or traditional medicines were not discussed with the Elders; nor was it my intention to do so. However, part of our discussion during the Elder's gathering was meant to clarify this through talking about my readiness as a learner of cultural teachings and knowledge and my intentions towards what would be shared. To clarify the information and knowledge that I sought in working with the women Elders, I use the terms cultural teachings and knowledge within this chapter to mean those traditional norms, teachings, and practices that are significant for Cree and Cree-Métis women's sexual health and overall health. In this way, cultural teachings and knowledge have already been shown to emerge in relation to the women's priorities in chapter six, such as female roles and relationships of the Cree and Cree-Métis.

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[28] Personal communications with cohorts Evelyn Steinhauer, Patsy Steinhauer, Claudine Louis, Lisa Bourque-Bearskin, Josie Auger, Rebecca Sockbeson, Lois Edge, and Cora Weber-Pillwax, and my Father contributed to the development of the perspectives that were used to analyze the work with the Elders.

### *Roles of the women Elders*

As stated in chapter four, the women Elders who participated in this research were from several Cree and Métis communities across Alberta. Similar to many of the Elders from many different communities across Canada, all of these Elders work with different Aboriginal communities in different capacities to address improving the health and well being of community members. All were female and are considered to be knowledgeable in the area of women's health and wellness within their communities. It is important to note that working with female Elders on this research was deliberate and would have direct impacts on what was learnt and how the research would proceed. In the context of this research, discussions regarding female roles and female cycles are most appropriately talked about with women Elders in light of the traditional teachings and practices that continue to be passed down through mothers and grandmothers. Female Elders would talk about these things differently than male Elders might and having male Elders present during these discussions would have necessarily and essentially changed the nature of the discussions. In fact, it is unlikely that male Elders would speak to these topics at all in a semi-public forum such as a research gathering focussing on women's sexuality and sexual health.

The role of the women Elders within this research was important to the outcomes of the research for two specific reasons. First, the women Elders could be viewed as fulfilling the role of co-researchers in this project. As the keepers of traditional teachings and knowledge, "teachers/Elders are respected as the historians and guides for individual and collective development" (Weber-Pillwax, 2003, p. 3). Elders as co-researchers would support the findings and outcomes of this research for several important reasons. First, one of the primary goals of their engagement in this research would be about my individual development, and this would be in addition to ensuring the development of further opportunities to help other Aboriginal women. In fact, the Elders spoke to this many times and each stated that her decision to participate was based on the desire to help me learn and the desire to help all women. Second, engaging Cree and Cree-Métis women in discussions of topics that are considered culturally significant, such as an Aboriginal woman's life-giving capacities/abilities, have been largely inaccessible to health researchers. Supporting and facilitating the women Elders to assume roles of co-researchers allowed them in non-coercive ways to make their own decisions, individually and collectively, regarding what would be shared. Third, these Elders possess special knowledge of Cree and Cree-Métis women's health and wellness in relation to their cultural traditions, teachings, and practices. Gaining deeper and more meaningful insights into the ways in which Cree and Cree-Métis women draw upon cultural teachings and knowledge regarding their own health and wellness concerns is less likely outside these contexts. Sharing responsibilities towards what could and would be shared between the Elders as co-researchers and myself as the researcher enabled a richer, more valuable, and culturally insightful piece of research. Working in this way further deepened our relationships, intensifying the principles of respect and trust. The women Elders' participation had direct impacts on the ways in which their information would be shared and this concern was reflected in the following statements by Marg Friedel:

> *I just want to say something. First of all…I would like a few minutes to think about it. Most researchers are so disrespectful with that. They throw something at you and they expect you to respond right away. Well, I don't do things that way. I have the answer, but I don't have it right now…. They expect you to just blurt it out when sometimes you need help to either remind you or to actually tell you what it is that you need to know, and then you can give a better answer. Then you know that what you're saying is done in a thoughtful way because if you just blurt out stuff, then it is disrespectful. It's always taken the wrong way. When you don't think about something and you blurt it out, it will not be what you really meant.*

The role of the women Elders within this research was also important to the outcomes of the research. What I would learn through working with them unfolded to validate the findings from the work with the women. This was an important source of triangulation for the data based on the women's interviews and validated the ways in which significant aspects of Cree life was manifested in the stories of the women. Miles and Huberman (1984) talk about the triangulation of data as a way to "support a finding by showing that independent measures of it agree with it or, at least, don't contradict it" (p. 235). In fact, what I learned from the women Elders in relation to traditional teachings and knowledge validated the findings of the work with the Cree and Cree-Métis women and those areas of priority that they themselves had identified in relation to their health and illness experiences. Mathison (1988) talks about "structural corroboration" as a means of triangulation of qualitative data findings and cites Eisner (1979) as defining these methods as "the process of gathering data or information and using it to establish links that eventually create a whole that is supported by the bits of evidence that constitute it" (p. 13/p. 215). The value of what I learned from working with the women Elders was "greatly enhanced" through my own realisation that their contributions could be used to triangulate the data findings from the women by establishing links between the traditional teachings and knowledge of the Elders and the ways in which Cree life were manifested in the lived experiences of the Cree and Cree-Métis women (Mathison, 1998, p. 13).

### *Working to Unfold the Processes & Teachings of the Women Elders*

In working to create safe and appropriate environments for the sharing of cultural teachings and knowledge, the women Elders also engaged in their own processes that would enable them to share and teach cultural knowledge. As discussed earlier, this included working to understand what was appropriate to share at this time and ensuring that I understood our mutual responsibilities in the sharing of cultural teachings and knowledge. As well, the Elders engaged with one another in their own processes according to their own practices and protocols. An important process that the Elders moved through may be understood through describing the Cree meanings of "Wahkohtowin". Translated into English language and concepts, academics would likely refer to and understand this as the group process. Although the purposes of such a process may be similar to those of non-Aboriginal peoples, I later came to realise how this process worked to reinforce the principles of the research. Additionally, the processes that emerged during this research within an Indigenous framework – ceremony, shifting, transformation, and relationality – would find further significance through working with Cree and Cree-Métis traditional teachers and knowledge holders or the Elders.

The "Wahkohtowin", as I understand it, means 'kinship' or a way of 'being in relationships'[29]. O'Rielly Scanlon *et al.,* (2004) support this in citing a personal communication with Cree speaker and researcher, Ermine (2001) in stating, "Wahkohtowin", a Cree word meaning kinship or the state of being related, is a fundamental concept for understanding Indigenous culture and traditional beliefs" (p. 1). As these Elders began to talk with one another, they told stories about people, relatives, and other Elders that they each knew. For example, Rita Auger and Isabel Auger (they are not sisters) told stories about their own parents, where they lived, how they lived, and the knowledge that they had of their culture. In this way, these Elders shared stories about their relatives that would help each other to understand where they each came from and how they each came to hold the cultural knowledge and the understandings that they could now share. This was important for two reasons. First, as I stated earlier, for many Aboriginal peoples, the test of knowledge is experience. Through telling their stories, each of the Elders was speaking of their own experiences. For example, Isabel Auger talked about the 'experience of life' and the education that she had learnt through the experiences of her human life when she stated,

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[29] I gained my understanding of this word in speaking to my Father and other fluent Cree speakers.

> *...the education that I learned was the education of the Mother Earth. The trees and the lakes where I was born and the rocks that I picked with my mom and all that. That's the education that I had.*

Second, I came to understand that going through this process with one another was a kind of preparation or ceremonial ritual (or shift) that would lead to their discussions regarding cultural teachings and knowledge in relation to Cree and Cree-Métis women's health and wellness. Gunn Allen (1986) refers to ceremony as a ritual when she defines ritual as "a procedure whose purpose is to transform someone or something from one condition or state to another" (p. 80). Graveline (1998) also refers to ceremony in this way and states that this may include, "[S]peeches, stories and songs [that] recall our personal responsibility to continually reestablish our links to each other and all of creation". Many of the stories that the Elders told about the people that they knew did 'reestablish' these links. Weber-Pillwax (2003) also talks about ceremony. Within her work on identity formation and consciousness of Métis and Cree peoples of Northern Alberta, Weber-Pillwax (2003) talks in depth about ceremony as an event. She states that the ceremony known as the Wi̱hkohtowin or 'dance of the ancestors'…is a spiritual event that ensures the continuity of a particular relationship between the people and the ancestors" (p. 128). What was important in relation to these different, but inter-related roles or meanings regarding ceremony, within my work, was to understand that their meanings of ceremony are embedded in 'collective experiences' – such as my interpretations of "Wahkohtowin" and the Elders 'moving through' the processes of "Wahkohtowin". In this way, the Elders entered into a kind of ceremonial space or participated in a collective experience that would serve as a preparation for the sharing of deep cultural knowledge that would take place.

Moving through this important process would reinforce the principles of the research as listening to and sharing these stories would work to further build the relationships of those Elder women engaged in the process. Further, the stories that were told often referred to the knowledge of the Elders and old people within these stories and would similarly reflect many of the cultural understandings and traditional beliefs of Cree and Cree-Métis peoples. For example, Isabel Auger talked about traditional dancing that she had participated in and its relationship to health and healing. She explained,

> *You feel good. When you're sick, you feel good because you move your whole body. And your mind, you're happy to see the children dance and you're happy to see the Elders dancing. You like to hear the Elder's stories or their laughing. It's a healing. You touch the Mother Earth and you feel good. That's how I heal myself a lot.*

As well, Alice Reid talked about the berries that she had gathered in different places and some of the kinds of berries that were used in ceremonies. Marg Friedel and Rita Auger talked about the midwives that they knew and some of the traditional practices regarding birthing. The Elders told stories about traveling to different places, visiting different people, and attending different ceremonies and cultural events. In this way, the Elders worked to establish a safe and trusting environment from which to share cultural teachings and knowledge and in doing so moved through their own processes, reflecting the ways in which Cree and Cree-Métis peoples relate to one another and to others in the world around them, through the cultural meanings embedded in "Wahkohtowin".

These inter-related processes that described "Wahkohtowin" as a collective experience illustrate that Elders work and teach in distinct ways. These distinct ways reflect their Indigenous ontologies and epistemologies, often evidenced in teaching through stories. Teaching through stories, from within an Aboriginal context, is pedagogy that is grounded upon communication systems of oral histories, traditions, and knowledge. Isabel Auger referred to this when she talked about the knowledge of Elders as medicine people. She stated,

> *They don't carry a book. They have it in here [points to her head] and it comes out from here [points to her heart] and they speak here the truth [motions to her mouth]. That's the way we were raised. So this is how it is.*

Weber-Pillwax (2003) also refers to the knowledge of Northern Cree and Métis peoples as being based in and communicated through orality. She further speaks to the significance and role of stories in communicating this knowledge in stating that Indigenous peoples "speak and teach in stories and metaphors because these can layer meanings" (Weber-Pillwax, 2003, p. 195). As described, the Elders in this work did proceed in this fashion. The majority of my learning from working with them was found within their stories. This reminded me of how my own Father would always begin talking to my siblings and me by saying, "Let me tell you a story". Towards the end of the one-day session with the women Elders, they commented on the many stories that they had told. Even though we had not discussed the experiences of the women I had interviewed in any detail, they were confident that I had learned what I needed through the stories that they had given me. Alice Reid stated,

> *I think there are lessons in the stories. The stories come with lessons and that's the thing. But that's the thing that our young people don't always understand. And then they think about the story months later and then they realize, what was that suppose to mean. It's sort of like a dream. When you have a dream, you wonder what the lesson was or what the learning was or why you had that dream.*

Part of the unique role that stories fulfill in Indigenous knowledge systems was described in chapter four. What I talk about here, in relation to stories, is how stories support the learning processes of Cree and Cree-Métis peoples (and this research from within an Indigenous framework) and the ways in which these 'layered meanings' are found within the stories of Elders. Stairs (1995) talks about the learning processes of Native peoples and the role of stories within this context when she states, "Native learners typically develop concepts and skills by repeating tasks in many different situations.... They do not traditionally make explicit verbal formulations of basic rules or ideas for success, but rather recount what they have experienced and listen to stories which present concepts and principles implicitly" (p. 141). The implicit nature of concepts and principles may often be, as stated earlier, in the form of a metaphor. The Elders did this often during our gathering as demonstrated by Rita Auger when she explained,

> *I'll tell you a little story. ...when you do the sweat lodge...there's something good in that that comes out. Why? Because when you're in your mother's womb you're inside. Just like in a sweat lodge, when you come out the Nurses wash you up. They just clean and wipe you up. When you come out of the sweat lodge...it's just like coming out again to a new life.*

Describing the role of the listener during the telling and recounting of these stories, Stairs (1995) further states, "[F]ormulations of the big ideas is left to the minds of the individual participants or listeners according to their own experience levels and perspectives" (p. 141). This role of the listener is a particular significant element in Indigenous epistemologies or the ways in which Indigenous peoples come to know what they know (Hampton, 1995; Stairs, 1995; Weber-Pillwax, 2001). Further, Goudreau (2006) talks about how a teaching needs to be heard seven times in order to learn its lessons and she refers to the 'Seven Grandfather Teachings' when she states, "[A] core set of traditional teachings shared by many Aboriginal communities is the Seven Grandfather Teachings of love, respect, honesty, humility, wisdom, truth, and bravery. Several of the Seven Grandfather Teachings were referred to by the participants in the sharing circle, individual interviews, and journals". (p. 78). Goudreau's (2006) referral to the need to hear a lesson seven times lends credence to the iterative value of stories and the reasons that they are told time and time again. Isabel Auger referred to this when she talked about the stories and their teachings:

> *You know what, this is a message. It's a message for healing...we talked about healing. How can we help our people? How can we help our children? Great grandchildren? A story tells us to tell you. How does it help you?*

### *Summarizing the work to unfold the processes and teachings of the Elders*

The processes that unfolded in the work with the women Elders also reinforced the principles of the research. Further, the research processes described as Indigenous processes of learning – ceremony, shifting, transformation, and relationality – were also significant in relation to the work with the women Elders. "Wahkohtowin" as a preparation or form of ceremony that the Elders moved through suggests that a 'shift' took place during the gathering that supported their own transformations. These transformations included what they experienced and learned from one another. The nature of Indigenous ontologies and epistemologies is inherent in these processes as these Elders consistently acknowledged their relations and demonstrated that these relationships continue to have impacts on the cultural teachings and knowledge that they share. This was further exemplified through their discussions on spirituality and through the recognition that these Elders always spoke about their knowledge as being "little" in comparison to the cultural teachings and knowledge that are held within the stories of their ancestors. These statements are made because traditional teachers and knowledge holders understand the nature of Indigenous knowledge and that there are layers of meaning embedded within cultural teachings and knowledge.

I stated in the earlier chapters that in doing this research, I struggled to see the connections or relationships between the work with the women Elders and my own learning from the stories of the women. Although I waited to see these connections emerge in tangible ways, they did not, in fact, materialise. I knew, however, that a deeper and more meaningful understanding of Cree and Cree-Métis women's health and illness experiences would not be possible outside of this context of work with the Elders. Although I could easily locate the significance of working with the women Elders in my own learning and personal transformation, the gathering of these Elders in one place at one time did not culminate in a process of formal data analysis. The processes that did unfold and what I learned from these spoke clearly in support of the principles that underlay the research and reinforced the appropriateness of the research protocols and activities generally in recognizing the overall benefits of using an Indigenous research framework to work with Cree and Cree-Métis peoples. Further, through the stories and teachings of these Elders, I found evidence and validation for the areas of priority that had been identified in the examination of the stories portraying the lived experiences of the Cree and Cree-Métis women. It was at this interface, between the women's stories and the Elder's teachings that I found many of the significant inter-relationships of my work to emerge. At this point, I now turn to the women's stories and talk about these in relation to the ways in which cultural teachings and knowledge support the health and wellness of Cree and Cree-Métis women. This discussion of these cultural teachings and knowledge will provide further insights into the significance of a cultural context for understanding the health and illnesses experiences of the Aboriginal women.

### *Building on the Stories & Lived Experiences of Cree & Cree-Métis Women*

In analysing the research contributions from the women Elders, I found relationships between their words and the data from the Cree and Cree-Métis women in those areas that the women had identified as being of priority in their health and wellness. As I looked at the areas of priority that had been identified by the women, I began to see that the Elders had spoken to each of these areas of concern. In some instances, the Elders spoke directly to the concerns and issues of Cree and Cree-Métis women's sexual and overall health; however, in other ways this connection emerged from their stories. During a conversation regarding these findings with fellow Cree-Métis research student, Lois Edge[30], we talked about a project that she had worked on for a number of years with Métis Elder Tom McCallum. The volumes of information and data collected during the project's four-year period with Métis Elders, healers, traditional teachers, and old peoples from several communities across Canada, Lois stated, revealed that the learning and teachings always revolved around four themes. In the paper, *Métis identity: Sharing traditional knowledge and healing practices at Métis Elder's gatherings*, Edge and

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[30] Personal Communication – Lois Edge. January 24, 2008. Edmonton, AB.

McCallum (2006) identify these four underlying themes in their discussions with the Métis Elderly as areas of importance or as the priorities that impact and contribute to the health and wellness of the Métis. These priorities are the importance of women and women's roles in the family, the need to return to our Aboriginal languages, the significance of relationships with land and water, and health and healing (Edge & McCallum, 2006).

Through discussions such as this one with fellow researchers and colleagues and in reflecting upon Indigenous Hermeneutics as a method of analysis in this research, I have found that much of the significance of the work with the women Elders emerged as I examined the transcripts in relation to the areas of priority that the Cree and Cree-Métis women had identified regarding their health and wellness. Meyer (2003) talks about the need for Indigenous researchers to move away from pathologizing the lives of Indigenous peoples through research when she asks, "Why nihilism?" (p. 250). She frames her discussion on Hawaiian Hermeneutics through asking, "[W]hy don't we see these negative statistics of our people as symptoms of something larger and potentially healing?" (Meyer, 2003, p. 250). Meyer (2003) further goes on to explain that when we understand that these larger systems are at work, we, as Indigenous peoples and researchers, are able to begin to understand "more of what's happening within and around ourselves" (p. 250). I came to realise that this had been the driving force behind my motivation to do this research. In other words, the development and implementation of this research process had always been about my desire to work with Aboriginal women on this particular topic that held the potential to further pathologize their lives, but which I was certain could also be addressed in ways that would 'liberate' them. As a health care practitioner and researcher, I had learned that health research with Aboriginal women often reduced them and their experiences to reports of "poor health status" and the tendency to participate in "risk-taking behaviours". With this motivation, then, it was apparent that the forms that the data analysis would take were crucial, not only for measures of validity and credibility but for the intention of 'liberation' from stereotypical and decontextualized data interpretation with its resultant dehumanization and sterilization of Aboriginal women's lives.

These analyses of my learning with the women Elders in relation to the data findings from the women's stories required a reflection of the contexts through which the findings would reveal their greater or deeper inter-relationships. This would then become the 'larger picture' wherein we might see the stories of these Cree and Cree-Métis women as pointing to a fuller and deeper understanding of the significance of culture for Aboriginal female health and wellness. Steier (1991) defines 'reflexivity' as a "turning point back onto a self" and a "way in which circularity and self-reference appear in inquiry, as we contextually recognize the various mutual relationships in which our knowing activities are embedded" (p. 163). Hampton (1995) describes 'reflective thinking' when he states that it "suggests a habit of mind that thoughtfully considers a speaker's words and seeks in them for what can be built on" (p. 25). Through processes of reflexivity and reflective thinking, I found the Cree ways of life to be manifested in the stories of the women. I saw them as the deep reflections of the cultural teachings and knowledge that emerged from my work and learning with the women Elders. I present these findings here. For the purposes of organization and clarification, I begin with the same area of priority that was identified first by the women in chapter six – mental, emotional, and spiritual health as significant for Cree and Cree-Métis women's health and wellness.

### *Mental, emotional, and spiritual dimensions of Cree and Cree-Métis women's health*

*The way of life is not a new truck or a new car or a new boat. You can have it, but those are not very important. Your life is important. Your health is number one. Without a mind, you can't hug yourself. So the mind has to be strong. (Isabel Auger, May 2007)*

In chapter six, I talked about the women as having identified several areas of priority in relation to their health and illness experiences. Through looking at the common characteristics or shared qualities that emerged from this discussion, I found that the stories and traditional teachings of the women Elders validated the manner in which the Cree ways of life were manifested in the experiences of the women. I begin by discussing the shared qualities carried within the women's stories and the Elder's stories and teachings in relation to the mental, emotional, and spiritual dimensions of Cree and Cree-Métis health and illness experiences.

I stated in chapter six that the women had come to understand that nurturing the mental, emotional, and spiritual aspects of themselves is just as significant to their well being as is physical strength and vigour. Throughout their conversations regarding traditional teachings and knowledge, and embedded within their stories, the Elder's also referred to the power of the mind, emotions, and spirit in relation to health and wellness. In particular, and similar to the women, the Elders talked about traditional teachings and knowledge that present the mind as a separate, but powerful dimension of the person. For example, Rita Auger stated,

> *Your mind, you think it's getting narrow now, but your mind is getting wider as you get old. I said, I keep forgetting, but the old woman said, your mind is getting wider not narrower.*

Isabel Auger also referred to traditional views of the mind as the most important part of your body when she said,

> *You can be in a wheelchair or on a bed and you can't get up, but this mind, this mind has to be for us, because it's the most important part of your body. Without your mind, you can't think. You can't help.*

The women also talked about their mental and spiritual health. In particular, they referred to emotional well being as having a significant impact on their health and wellness. The Elders also referred to the importance that traditional teachings and knowledge place on emotional well being. Isabel Auger illustrated that this was integral to her own health and wellness when she stated,

> *People say, how can you still dance? That's part of my health. ...because you move your whole body. And your mind, you're happy to see the children dance, and you're happy to see the Elders dancing. You like to hear the Elder's stories and the laughter. It's about healing. That's how I heal myself a lot and you feel good. You touch the Mother Earth. And all the outfits for my sixteen grand children, I made myself and brought them. To bring that feeling...is a good feeling.*

The majority of the women also spoke about their spiritual well being. Marla spoke about the power of prayer and asking for what she needed to make herself well. This demonstrated that her spiritual well being had a significant impact on her overall wellness. Throughout the one-day session, the women Elders spoke about traditional teachings and knowledge that view spiritual health and wellness as integral to overall health and wellness. Further, traditional teachings related to spiritual well being were seen as having significant impacts on individual health and wellness. For example, Alice Reid explained,

> *You know a lot of things are written down about how we treat people and care for people. We can talk about how we get the disease, but in our spiritual teachings, we always say there are two kinds of diseases. One is material and one is spiritual. It doesn't mean our body doesn't have a disease or it doesn't wear, but it doesn't have to affect our spirit. Whether it's cervical cancer or breast cancer or any kind of cancer, we have to go back to the source. What happened to us in our spirit? We tend to forget our spirit...it's not written in the PhD books. If the spirit is strong, life is good.*

Alice talked about diseases that affect these different, but entwined parts of an individual and referred to traditional teachings and knowledge that view identifying the sources of illness in relation to spiritual needs as necessary for healing. In this way, the traditional teachings of the women Elders were shown to view the spiritual dimension of a person as a living and separate, but deeply inter-connected dimension of the person. Throughout their stories, the women talked about mental, emotional, and spiritual health and alluded to these as dimensions of themselves. Further, caring for and nurturing these dimensions of themselves were seen as critical to their health and illness outcomes. Marg Friedel also spoke to the nurturing of these dimensions of a person through traditional practices and ceremony when she stated,

> *We'll make a place to build a sweat lodge. And each sweat holder will come there and do their sweat lodge in their own way. It's for healing. Whether it's for spiritual healing, body healing, physical healing or even the mind. You know emotions. It can all happen there.*

In referring to the role of the sweat lodge ceremony in healing the different dimensions of a person, Marg Friedel talked about the body, mind, and spirit as separate, but inter-connected entities. Isabel Auger also spoke about other traditional teachings that view people in this way when she stated,

> *Animals will never hurt you because they see your heart. They see your mind, body, and spirit. If you're afraid of them, they're going to attack you for sure. But if you don't, if you're kind and you talk to them, it doesn't matter what kind of animal it is [they won't hurt you].*

The ways in which the women cared for themselves, as discussed in chapter six, were grounded in similar understandings regarding connections and inter-relationships among mind, body, and spirit. They talked about 'mental power' and a 'knowing' of the mind as playing a crucial role in health and healing. The Elders also used words like strength, power, and knowing when they talked about traditional teachings and knowledge in relation to health and healing. They also talked about these words as being characteristics of the different, but inter-connected dimensions of themselves. For example, Rita Auger stated,

> *You have to be strong minded. A strong mind and a strong heart.... The strength and power you have and your spirituality and your willpower in your life and your body – you look after it.*

Mental power and knowing were intimately tied to traditional teachings regarding the spiritual dimension and spiritual wellness of a person. Isabel Auger stated,

> *But you have to have [a really strong spiritual] connection. You have to be strong to be cured. You have to really believe.*

Further, the women spoke about their health and illness experiences in ways that revealed that the impacts on their health and wellness were much more than just physical. The stories and teachings of the Elders validated these findings through their own discussions, speaking to the connections between nurturing the mind, body, and spirit and healing these dimensions of the person. Alice Reid exemplified this during the Elder's gathering regarding traditional teachings and knowledge that are viewed as crucial to meeting the health and wellness needs of Aboriginal women. She explained,

> *What is it that we need as Aboriginal women? To get the message across that there are certain ways of doing things for us. One of them is to first see that we are all spiritual beings. We live in a physical body and our physical body falls apart a lot of times. We live in our physical bodies and it holds our spirit. And we must learn to respect and honour that.*
>
> *This is what happens in the world of academics. Sometimes what I have seen in this world throughout my nursing career is this disrespect of humans. Disrespect of people who are a different colour, a different background, a different ethnic background, even the poor who come off the street, the grubby, the messy – those people are not respected because people do not see the spirit.*

In summary, the stories and experiences of the women identified that they place the greater significance of their health on their mental, emotional, and spiritual dimensions. This was noted in the ways that the women talked about these dimensions of themselves as having important impacts on their health and wellness. The Elder's stories and traditional teachings were shown to support this position of the women and to validate the ways in which Cree life was manifest in the lived experiences of the women. This was evidenced in the traditional teachings and knowledge of the women Elders who also spoke about the mind, body, and spirit as separate, but inter-connected aspects of the self. Further, the stories and traditional teachings of the Elders built upon the data and findings of the women's stories as the Elders identified that the mind and spirit play important and deeply inter-related roles in the health and wellness of individuals. As well, the Elders identified traditional teachings and knowledge that recognize the need to nourish mental, emotional, and in particular, spiritual dimensions of oneself in order to heal and live well. Healing through participation in traditional activities and cultural practices, such as the sweat lodge ceremony, was identified by the Elders as integral to the health and wellness of Cree and Cree-Métis peoples.

### *Healing from abuse and violence*

In chapter six, the stories of the women revealed that they have experienced multiple forms of abuse and violence. As well, several of the women talked about the kinds of intrusion that they have experienced during their lifetime from different governmental service departments, such as health and social services. These experiences of the women had often been described as replications of the experiences of their own mothers and grandmothers, further suggesting significant needs for healing in relation to these women and their health and wellness. Feelings of isolation, damage to self-esteem, and a lack of information and knowledge regarding female sexual and reproductive health were some of the lasting and lingering effects and impacts on the health and illness experiences of these women.

The Elders all spoke about many of these issues during our visits prior to the one-day gathering and also during the one-day session. For example, during a visit prior to the gathering, Rita Auger had talked about the need to return to some of the cultural teachings in relation to the sexual and reproductive health of young women. She had referred to the current lack of understanding and knowledge of these teachings and practices among young Cree and Cree-Métis women. She further identified the significant teachings around the traditional roles of mothers and grandmothers in the onset of young women's menses, and had stated that this loss has had impacts on the ways in which many contemporary young Cree and Cree-Métis women understand and treat their bodies. Rita had also talked about the traditional views of the sacredness of 'moon time' in the life of a Cree female when she stated: "women were taught at a very young age – the younger a girl gets her moon time, the healthier she was thought to be!" I would later find out that many of the women who participated in this research also referred to many of these teachings in relation to 'rites of passage'. However, the majority of these women talked about their limited knowledge regarding these cultural teachings and practices and emphasized their potential value regarding the development of positive self-images and self-esteem among Aboriginal women generally.

During our visits prior to the gathering, both Isabel Auger and Rita Auger had also talked about cultural teachings that were meant to teach women lessons of cleanliness in relation to care of the female body. For instance, Rita Auger had stated that women did not wash their clothes with the men's clothes. In telling her story, Marla talked about cleanliness many times. She referred to the teachings and lessons that the women Elders spoke about when she stated,

> *[My grandmother taught us about]being clean in taking care of yourself as a woman. To make sure that you were putting things in clean places and that you weren't cross-contaminating stuff, things like that. Like wash your hands afterwards and make sure you shower afterwards if there is a shower. If you have to hall water, then do that. You were always washing with clean water.*

Further, Isabel Auger had stated that these teachings were important and that women's lack of understanding regarding these lessons has contributed to the development of some of the diseases that we see today, such as the cancers of the female sexual and reproductive systems.

Feelings of isolation, damage to self-esteem, and a lack of information and knowledge regarding female sexual and reproductive health were recognised earlier as having had significant impacts on the lived experiences of the women who shared their stories. These issues are also referred to in the work of Anderson (2000), *A recognition of being: Reconstructing Native Womenhood.* The work with the women Elders was shown to build on the need to address abuse and trauma in the lives of Cree and Cree-Métis peoples through their recognition and discussion of these issues. Marg Friedel spoke at length regarding the health and healing needs of urban Aboriginal peoples. During this discussion, she acknowledged abuse and trauma as current concerns of urban Aboriginal peoples. Marg stated,

> *Today you cannot let your kids go out on the street because there's somebody there that's going to sexually abuse them or hurt them or kidnap them and that happens every day. You can't send your kids out to play anymore.... For people that have been here for three or four generations, and some of them are poor, they don't go out of the city very often or they don't have a vehicle, so if they know there's a ceremony here or there, they can't go.... So, how do we bring the healing?*

Marg referred to the environment in which many Aboriginal peoples find themselves today. Alice Reid also spoke about these issues. In the following excerpt, Alice talked about the challenges of healing for Cree and Cree-Métis peoples in unfamiliar environments:

> *I can just imagine what it must be like for our Elderly who have to go into the hospital. What it must be like for them. Not only are you dealing with their bodies,*

> *but if they live in the country, they hear different things, feel different things. You can hear the birds and the water splashing and the rain on the windows. You can hear the frogs. You can hear the silence. What happens is you bring that person to the city where they often get treated, and there is such a bombardment of the unfamiliar noises coming from all directions and unfamiliar smells and unfamiliar people. ...and you come to this and you expect our people to heal from cancers in this environment. It's not possible. It's not possible because you are so far out of what you need to do to heal. Those are the things that need to come out when you're talking about our women.*
>
> *What happens to women who have had cervical cancer and what are the ways for it to be easier for that woman to understand what's going on. How do we understand it? How do we examine it? Simply by saying things like, right now we are doing a cervical cancer clinic up in Wabasca and that clinic is being held every Friday and is being done by Nurses now.*

In addition to providing further collaboration for the findings of research by other Indigenous scholars, the work with these women and my learning from the Elders has provided sound indications to me about the need for relevant health research and improved service delivery in the care and treatment related to Aboriginal women's sexual health and wellness. This understanding has been highlighted in the words and wisdom of the women Elders involved in this research. Traditional knowledge holder and Nurse Practitioner, Alice Reid spoke directly to some of this care and treatment of all women when she explained,

> *I used to do a lot of Pap smears as a Nurse Practitioner. Women are more comfortable having women do those exams. There is a need to make this more available in clinics and to train the staff. We need to do more to assist women, not just in the Aboriginal culture, but the women of society, to be able to accept our femaleness, our womaness, and to know that there are ways to be treated without*

> *having to be embarrassed about it. That's what we are trying to verify – how we look after our Aboriginal women in such a way when there was a time when women didn't want to be undressed. Then they put them in the hospital and they strip their clothes off. And they want to bathe them from head-to-toe and there's ways to do that without stripping all of their clothes off or are we taking them off and exposing them all. So there are many things to be taught in our Nursing schools related to how we manage and look after women. There's different cultures, ours being one of them. Sometimes women just don't want to tell you.*

In closing this discussion, it was also stated that the women alluded to a significant need for healing in relation to their health and wellness with regards to abuse and trauma. This has been noted throughout the chapters based on the interviews with the Cree and Cree-Métis women and through my own descriptions of my learning through the work with the women Elders and their recognition of the need for healing within their communities. Although the women and the Elders all spoke about abuse that they have experienced and the healing of Aboriginal peoples generally in these regards, further research and expertise would be required in this area in order to provide a comprehensive and informed evaluation of the impacts of intergenerational trauma, sexual abuse, and violence on the sexual health and wellness of Cree and Cree-Métis women. The personal experiences with sexual abuse and violence were identified in a previous chapter as an area of priority for the women in this study as the affects and impacts of these forms of violence on sexual health and wellness were described as isolating, self-deprecating, and often leading to a lack of knowledge regarding sexual and reproductive health for some of the women. It was also noted that while historical trauma was instrumental in introducing harmful and damaging views of Aboriginal women to society, many Aboriginal peoples continue to experience physical, mental, and sexual forms of abuse, including sexual exploitation. The need for healing from abuse and trauma in the lives of Cree and Cree-Métis women is not discussed outside these contexts within this document.

In summary, the Cree and Cree-Métis women involved in this research talked about abuse, violence, and intergenerational trauma that they have experienced during their lifetime. The impacts of these on the health and wellness of Cree and Cree-Métis women was noted through their identification of this area as a priority of concern in their lives. A lack of knowledge and understanding regarding cultural teachings and knowledge in relation to sexual health was one area that the women Elders focused on during our visits. This was shown to validate the experiences of the Cree and Cree-Métis female participants and to build upon the data findings of the work with these women as the Elders provided further understandings of the Cree and Cree-Métis cultural teachings and knowledge. In addition, the Elders provided sound teaching and instruction regarding the care and treatment of Cree and Cree-Métis women in relation to their sexual and cervical health. In concluding this section of the chapter, the need to address healing from abuse and trauma in the lives of Aboriginal peoples was discussed.

## _Loss of cultural teachings and knowledge_

> *"Lived experiences shape identity and give reality to autonomy. Identity shapes lived experiences and embodies autonomy. Autonomy gives meaning to identity and can determine the shape of lived experiences. It is understandable then, that Indigenous people tend to see all lived experiences as sacred since the human being is a sacred being, and it is impossible to isolate identity from lived experiences". (Weber-Pillwax, 2003, p. 40)*

Within this section of the chapter, I refer to the stories and teachings of the Elders that suggest the loss of cultural teachings and knowledge are significant for the identities of Cree and Cree-Métis peoples. Discussion in relation to Cree and Cree-Métis female identities, within the sections of this chapter, relies on the findings of the work by Weber-Pillwax (2003), *Identity formation and consciousness with reference to Northern Alberta Cree and Métis peoples.* This is for two specific reasons. First, with the exception of Elder Marg Friedel, all of the women, Elders, and communities involved in this research were Northern Alberta Cree and Métis peoples. Second, in analysing the women's lived experiences, I found it increasingly difficult to deny that the significance of culture for the health and wellness of these women emerged in ways that were couched in perspectives of Aboriginal identity. Weber-Pillwax (2003) supports these findings in stating that, "lived experiences, whether viewed from an individual perspective" (such as the perspectives of the women) or from "a collective perspective" (such as the perspectives of the Elders), "are the expressions of identity and autonomy" (p. 40).

Throughout their stories, as discussed in chapter six, the women talked about the loss of cultural teachings and knowledge as having significant impacts on their lives. What I learned from working with the Elders was that cultural teachings and knowledge would support these findings in several important ways. First, the cultural teachings and knowledge that were found within the stories of the women Elders were shown to support and validate the findings of the women's experiences in relation to cervical cancer. For example, two of the women stated that they were pregnant when they received their diagnoses of cervical cancer. I suggested in chapter four that the women's feelings of pain, fear, and anxiety showed evidence of exacerbation during pregnancy which may have been related to the invasive nature of cervical cancer treatments and procedures. Within the Elder's stories, traditional teachings would emerge in relation to Cree and Cree-Métis women and childbirth. These traditional teachings would refer to the sacredness of women and childbirth and the delicate, but powerful condition of women during menses and childbirth. For instance, during a visit with Rita Auger prior to the one-day session, she had talked about traditional views and teachings regarding the sacredness of women and childbirth. Rita stated,

> *Everything in a woman's life was so sacred a long time ago, but since then the people have mixed it up…now they teach children about sex in school.*

A great deal of how I have come to understand the relationships between traditional views of the powerful and delicate conditions of a woman during pregnancy and childbirth and the significance of these for Cree and Cree-Métis women's sexual health and illness experiences would emerge from the stories of the Elders in relation to the role of midwives within their communities. Rita Auger spoke about this when she explained,

> *Not all women were midwifes. They were gifted. Gifted from the Great Spirit. They were gifted to deliver the babies at home. I haven't heard of one to lose a child while delivering at home. The children were sent out and nobody was allowed in except the women and the midwives. Even the children were sent out with the father to talk to him.*

This excerpt by Rita referred to traditional views regarding the sacredness of women during childbirth through stating that only the women were allowed entry during this time. As well, the activities of the men and children during this event were identified and talked about in relation to their traditional roles during childbirth. She further explained,

> *The midwife said that when a woman had a baby, her life was like a strand of hair. This is how she could easily come to harm or die when giving life.*

Rita referred to traditional teachings and knowledge that view the condition or state of a woman during pregnancy and childbirth as delicate through her statements that the life of a Cree woman is considered to be 'like a strand of hair'. Alice Reid also talked about traditional teachings and views of women and childbirth in relation to her experiences with midwives, which included her mother and grandmothers. She explained,

> *I'm a daughter of a midwife. My grandmother was a midwife, on my mom's side.... I use to attend with my mom, as a child when she'd go, I was always a helper...and you had to understand about pain and you had to understand about blood. And all the things I'd have to understand....*

Alice referred to traditional teachings and knowledge as having to 'know about blood' in relation to childbirth. This is congruent with traditional teachings and knowledge that view menses and menstrual blood as the source of an Aboriginal woman's power. Anderson (2000) talks about Aboriginal women's traditional sources of power when she states, "the menstrual period was understood as a time in which women exerted a phenomenal amount of power that precluded them from taking part in certain ceremonies" (p. 75). The stories and teachings of the Elders also supported these findings of Anderson (2000) in that Cree and Cree-Métis women are seen from a traditional point of view as possessing power during menses. This was revealed through the Elder's stories that talked about women as not attending certain ceremonies or events during menstruation in order to avoid harming others.

The sacredness that was traditionally afforded Cree and Cree-Métis women during menses and childbirth speak to the delicate and extremely powerful situation of a woman during these times. It is not a great leap then to realise that the invasive nature of cervical cancer procedures and treatments, such as those experienced through medical diagnosis, would be exacerbated by the failures to recognise these conditions or states of women while they are carrying children. Moreover, the stories and teachings of the Elders, such as Rita Auger's referral to the 'mix up' or confusion that the loss of traditional teachings and knowledge (with regards to sex and sexuality) has produced, reinforced, and validated the descriptions shared by the women of their feelings of pain, fear, and anxiety in relation to their cervical cancer experiences.

The second way in which the stories of the Elders supported the findings of the women's data in relation to the impacts of the loss of cultural teachings and knowledge for the health and wellness of Cree and Cree-Métis women was found through the significance attached by the women to the loss of their Native language. How this impacted the health and wellness of these women would be further understood through analysis of my own learning after working with the Elders. These impacts were referred to within the stories and traditional teachings of the Elders as the abilities to speak and understand one's language and this ability was viewed as critical to the health and wellness of Cree and Cree-Métis women. This was identified several times throughout the gathering with the Elders and was viewed as significant in relation to the healing of Aboriginal peoples. Isabel Auger stated,

> *The language. The language. You have to have the language to be able to listen.*

Isabel Auger points to the abilities to speak one's Native language as enabling access to cultural teachings and knowledge that have benefit for the health and wellness of Cree peoples, such as through the lessons for healthful living that are found within the teachings. Without one's Native language, the potential benefits of the teachings and knowledge (and their inherent lessons) are skewed or lost altogether. Cree researcher, Patsy Steinhauer[31], spoke to this issue during the session that I attended in order to access the Cree data of the Elders. She stated, "[W]hen the language is translated, the meaning becomes smaller. It's limited". Rita Auger further supported this when she stated,

> *Native culture and education, you have to talk your language. It has to go hand in hand. As Cree people…that's how we survive.*

All of the women spoke about the loss of their Native language in ways that expressed feelings of remorse and, at times, feelings of duress. As noted in chapter six, all of the women talked about this loss as a source of frustration in relation to their health and wellness experiences. Although this is not new information in terms of available research on the impacts of the loss of language and culture for Aboriginal peoples, these findings are significant in relation to the sexual health and illness experiences of Aboriginal women and are shown to validate the lived experiences of these women.

As well, analysis of the impacts of the loss of cultural teachings and knowledge on Cree and Cree-Métis women's health and wellness demonstrated that the women's strongest sense of loss was connected to the 'sense of oneself' as a Cree or Cree-Métis female. I have stated throughout this research that an Aboriginal person's sense of the self is grounded in their relationships to the world around them (Weber-Pillwax, 2003).

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[31] Personal Communication – Patsy Steinhauer. December, 2007. Edmonton, AB.

Through analysing the stories of the women, I found further evidence for this within the women's stories wherein they discussed the loss of cultural traditions, practices, and activities in the context of relationships as these were often embedded within the women's participation in such activities. This was also evidenced in the stories shared by the women Elders who spoke to the importance of gatherings and gathering activities. For example, as stated earlier, all of the Elders told stories about the people that they had known or presently knew, the places that they had travelled to, and the cultural activities that they had engaged in during these visits. Isabel Auger stated,

> *We used to camp for a week to visit them. And the old people used to gather up and just tell stories. We had some food and they'd play games.... They'd sing songs when we got there. We'd sing together before we came home.*

The significance of the loss of cultural teachings and knowledge included the loss of participation in cultural traditions, practices, and activities. Embedded within the stories of the women and the stories and traditional teachings of the Elders was the significance of these activities: the individual ability to participate in these activities was directly connected to the ability to maintain and preserve the important relationships that were held to parents, grandparents, relatives, and community, and indirectly to individual health and wellness. Further support of these findings is found in the work of Goudreau (2006) that explored the connections between women's hand drumming and health promotion. She states, "[D]rums draw communities together; the steady beat of the drum acts as a magnet that brings people together. An Elder told me, "When you hear drumming you go because that is where everybody is" (Goudreau, 2006, p. 100).

In a similar way, these Cree and Cree-Métis women talked about their involvement in cultural traditions, practices, and activities within the previous chapters and demonstrated the importance or value that they placed upon these activities. The health benefits would be realised through the positive and valuable sense of themselves that the women gained through participating in the traditions, practices, and activities of their own peoples. For example, Agnes stated,

> *When I went to a sweat lodge everything became clear. Everything.... It was being aware of who I was in that particular moment and the strength that I gained. That was probably one of the most enlightening times in my life. That day.*

Marla also referred to a traditional way of life and talked about the significant relationships that she associated with this when she explained,

> *I was watching how they were. Just [my grandparents] locations and where they chose to live or where they did live. It was really self-sufficient to plant a garden.... We had a u-pick farm so we were out in the fresh air all day long. There was never a lazy moment. It was the right foods. Fresh vegetables and wild meat. I think treats were garlic and grapes. Those were our treats. Raspberries, strawberries those were out treats. And [my grandmother] canned everything. Berries, her meat. We were just so self-sufficient. I miss that.*

In summary, this section has focussed on the ways in which the cultural teachings and knowledge of the women Elders have reinforced the identification of loss of language and culture as an area of priority for Cree and Cree-Métis women's health and wellness. The Elder's teachings were shown to validate the lived experiences of these Cree and Cree-Métis women. The stories and traditional teachings of the Elders suggest that the cultural meanings attached to the cultural teachings and knowledge are embedded and reflected in the identities of Cree and Cree-Métis peoples. As such, the loss of cultural teachings and knowledge and their inherent cultural meanings is also impacting contemporary Cree and Cree-Métis women in their struggles for healthy lives and strong Indigenous identities. What I learned from working with the Elders validated the lived experiences of the women in relation to the impacts of this loss of cultural teachings and knowledge for their health, healing, and wellness. In particular, these relationships between loss of traditional teachings and knowledge and the health and wellness of Cree and Cree-Métis women found significance and expression through the cultural meanings that were described by the women as signifiers of the loss of their own sense of themselves as Cree/Métis females (identity). Cultural meanings include traditional teachings and views about the significance of Cree and Cree-Métis women's traditional sources of power, such as menses and childbearing abilities, and the sacredness for the sexual and reproductive cycles of women. Further, the cultural teachings and knowledge of Cree and Métis peoples that are found within the stories of the Elders are often grounded in and communicated through the traditional languages of the people. Therefore, the capabilities of Native languages to meaningfully and appropriately convey the lessons for health, healing, and wellness through traditional teachings and stories provides evidence of the power and capabilities of these languages and further validates the significance that the women placed on the impact that the loss of their Native culture and language is having on their health and wellness.

### *Traditional teachings and knowledge*

> *Indigenous personal and social reality exists in a perpetual state of continuous interactive relationship that crosses the boundaries of time and space. For the individual, this state of perpetual relationship results in a personal sense of fluidity around notions of identity and consciousness. (Weber-Pillwax, 2003, p. 2)*

In chapter six, I stated that an examination of the women's health and illness experiences revealed that they drew upon cultural teachings and knowledge in caring for themselves and that this was shown to have positive impacts on their health and wellness. Cultural teachings and knowledge, in this way, emerged as valuable sources of knowledge that provide the tools for living healthy and living well. This includes traditional views of the values that are required for healthful living, positive self-images, and the importance and role of relationships in learning, experiencing, and expressing these positive reinforcements of oneself – or those things that are associated with identity. The stories and traditional teachings of the women Elders validated and built upon these findings again in several ways. First, the Elders talked about the traditional values that they had learnt and spoke about them as tools that lead to a successful life. Isabel Auger stated,

> *Kindness, that's the view to know the values that we've been taught.... Values are here to show you the path.*

In this excerpt, Isabel talked about traditional values as leading to a successful path or successful life. Other cultural teachings found within the stories of the women Elders that spoke of traditional values or 'tools' that are needed for these successful outcomes in life included listening and learning from parents and old peoples, speaking the truth, helping others, and respect. The importance and role of respect in working with Aboriginal peoples was exemplified throughout this research. The Elders talked about traditional views of respect for individuals, the power of women, animals, other cultures, their ancestors, the Creator, and cultural knowledge. Alice Reid also spoke about respect as a basic principle in relation to caring for Aboriginal women. She explained,

> *I remember growing up in a home, well ours always had a divider in it. Some of our neighbours only had one room. The men, the women, the children, the boys, the girls all slept and dressed and ate and everything in this one room. We learned how to change clothes in front of somebody else in one room. You know, you put the blanket over yourself and put your clothes on, and you never saw anybody's naked body. Never. You learn to do those things or you send the male people outside while you are doing it, while you're getting dressed. You were dressing in privately, underneath the sheet and in hospitals we try to do that with clients and a lot of times that is not respected. I mean a lot of those things are not respected. And some of those messages just have to be told time and time again. And brought out, even though it's a simple principle of privacy and respect. It still has to be taught and brought out time and time again.*

As well, the stories of the women revealed that cultural teachings and knowledge had contributed to their positive self-images. This was described in chapter six through discussing the ways in which the women retained a sense of value, self-worth, and independence of themselves, despite the 'shamed based orientations' that had been introduced to Aboriginal societies by the Christian churches. For example, Madelaine talked about humbleness as a traditional value or lesson that she had learnt from her mother and all of the women talked about independence as critical to their health and wellness. The stories and traditional teachings of the Elders reinforced these perspectives of the women. The women Elders themselves, demonstrated humbleness through the ways in which they spoke about cultural teachings and knowledge. Isabel Auger stated,

> *I think you know, I'm just learning myself.... We will fit [the stories and teachings] in a summary that we want it. It'll fit in there. The space is there where we can [share that]...so you understand those things.*

As well, the women Elders talked about traditional views with regards to the importance of listening to and learning from the old people. The value in doing this was talked about as a way to know and understand oneself as an Indigenous person. Within her story, Marla talked about her sense of herself as being intimately tied to her grandparents when she stated that 'you come to know yourself through spending time with your grandparents'. Through the stories of the Elders, I found cultural teachings that validated Marla's understanding of her sense of herself as embedded in her relationships with others. In closing this section of the chapter, I talk about the importance and role of relationships in learning, experiencing, and expressing one's identity as an Indigenous being and how this emerged from the health and illness experiences of the women.

Weber-Pillwax (2003) talked about the significance of relationships with ancestors in relation to Indigenous identity formation when she stated, "Cree and Métis experiences validate the importance that ancestors have in individual identity formation and consciousness…what is to be realized…is that Indigenous individuals live out their on-going relationships with their ancestors as part of their present and unfolding identities" (p. 153). The women's stories revealed that the meanings of health and illness are embedded in their relationships with others and the world around them. This included relationships with family members living and now gone, their relationships to the environments in which they lived, and for several of the women, their spiritual connections and relationships to a higher eminence. The Elders validated these experiences of these Cree and Cree-Métis women in their discussion about the meanings of health and illness as intimately tied to the health of Mother Earth. Recognition of the Earth as a living, breathing organism was seen as critical to the health and wellness of all people. For example, Isabel Auger spoke about traditional teachings with regards to traditional medicine and the view that the Earth is a living, breathing entity when she stated,

> *...because if you don't ask for that in the proper way, it doesn't matter what you do with it, it won't work. We were taught that, our moms, the old people used to say you have to ask for it in the proper way. It's alive. The Earth is alive like you and me.*

The importance of relationships to the health and healing of Cree and Cree-Métis peoples was also evidenced in the stories and cultural teachings of the women Elders. Goudreau (2006) also refers to the significance of relationships in the health and healing of Aboriginal peoples. In the following excerpt, she talks about healing as 'extending to the community':

> *With hand drumming, healing takes places at the physical, mental, emotional, spiritual, cultural and social (communal) level, sometimes obviously, sometimes subtly, in ways that are beyond our understanding. Participants in this study talked specifically about physical and emotional healing from the hand drum. Moreover, the healing occurs not only with the drummers; it also extends into the larger community. Healing in the Aboriginal society is encouraged at the*

> *community level unlike, European society, which has a tendency to individualize healing (Goudreau, 2006, p. 107).*

The stories and traditional teachings of the Elders may be viewed as validating and building on what was learned from the women's stories with regards to the significance of relationships for the health and wellness of Cree and Cree-Métis individuals. The Elders talked about significant relationships and connections between and among their ancestors, Mother Earth, the spiritual realm, and the Creator. The significance of these relationships emerged through the Elder's stories as the sources of cultural teachings and knowledge. For instance, Rita Auger spoke about traditional teachings and knowledge with regards to the cultural significance that is placed on the relationships between Cree peoples and Mother Earth when she stated,

> *When you step on a piece of grass barefoot, it's just like curing yourself because you are stepping on some roots.*

Isabel Auger also referred to many of these relationships as the sources of cultural teachings and knowledge when she explained,

> *It's time to speak up. Me and you. A lot of times, [we had hard times], but we made it somehow. Our families were close, even through residential schooling. The trees, the medicines, the waters are so powerful. I think, no I'm sure that they left something for us – you and me [pointing to other Elders]. Not to give up. No matter what happens.*

Marg Friedel referred to traditional teachings and views of ancestors as important and ongoing sources of cultural teachings and knowledge for the Métis when she stated,

> *...we are in a time when we have to go back to our ancestors. The healing that [we talk about now as Métis peoples] sometimes doesn't recognise the healing of*

> *our ancestors…. I have very strong Irish ancestors and they used the [ceremonies and methods that we are talking about now] too. In the 1800's, they killed all the healers. They hung them and burned them at the stake…their spirit fire was burning and after they killed all those spiritual people, it never came back for a long time. But our flame didn't go out and it's coming back everywhere [across the world] and we have to pay attention. We have to pay attention now to our ancestors because they are all around us.*

As well, Alice Reid referred to traditional teachings and knowledge with respect to the spiritual realm and talked about this as a source of Elder's knowledge when she stated,

> *I call it the knowing because that is the part they don't seem to understand about Elders and how we know the medicine. Sometimes it comes naturally and sometimes it's a learned skill. When we grew up, we were taught how to learn, how to know. So there's different ways of knowing and that's what the books don't tell you. The academic books don't understand that because they have to go through all the scientific teachings to find a way to understand it. But there is another world and I think that not just our culture knows that. We have other cultures that know that.*

Finally, the stories and traditional teachings of the Elders validated the ways in which Cree life were shown to have emerged from the lived experiences of the women by demonstrating that cultural teachings and knowledge work to reinforce positive Cree and Cree-Métis female identities. For example, as illustrated in chapter six in relation to the role of ceremony as a vehicle for cultural expression and healing, the traditional practices and ceremonies that the women participated in were found to enable positive expressions of themselves as Cree and Métis women. Goudreau (2006), throughout her work, also referred to the significance and role of the traditional practice of women's hand drumming as allowing for the expression and reinforcement of a positive Aboriginal female identity in her statement, "[B]eing able to practice traditions such as drumming and be part of Aboriginal hand-drumming circles allows Aboriginal people to identify with who they are" (Goudreau, 2006, p. 78).

With regards to the stories and traditional teachings of the women Elders, I identified that they talked about the positive cultural images of Cree and Métis women that are reinforced through traditional practices and ceremonies that acknowledge the sacredness and life-giving abilities of women and the power of women that is associated with this. Additionally, I have heard other Elders talk about ceremony as viable and successful means of treatment for mental health concerns, such as depression. Although the women Elders involved in this research did not specifically speak to cultural teachings and ceremony in the treatment of a mental health illness, they did talk about cultural practices and ceremonies that supported the mental and spiritual transformations of the individual, including the sweat lodge and the shaking tent ceremony. In this way, they talked among themselves regarding the many avenues that traditional practices and ceremony provide for addressing the mental and spiritual health and wellness of Cree and Cree-Métis peoples. Moreover, what arose as significant for Cree and Cree-Métis women in relation to their health and illness experiences was found in the recognition of the importance of relationships and inter-relationships of all of these to the health, healing, and wellness of individuals. Isabel Auger summarized traditional views on the significance of relationships and inter-relationships for Cree and Cree-Métis women's health, healing, and wellness when she stated,

> *It's good to learn because we are talking about the healing. It's all related to me in the stories of the Elders and everybody that was here…we are talking about cancer and how these things are all related to [the development of]cancer. Isn't that what you are looking for? That message.*

In summary, many of the women's positive reinforcements of themselves were shown to emanate from the cultural teachings and knowledge of Cree and Cree-Métis peoples. These were also found within the stories and traditional teachings of the women Elders, which were then shown to validate and build upon the health and wellness experiences of Cree and Métis women in relation to the Cree ways of life as manifested in the lived experiences of these Cree and Cree-Métis women. The significance of this was realised as cultural knowledge and teachings were shown to provide the values and lessons that are believed to lead to a good life, to enable and reinforce positive Cree and Cree-Métis female self-identities, and to validate the importance that the Cree and Cree-Métis women had placed upon their relationships to others and the world around them. As well, cultural traditions and practices, such as ceremony, were shown to be vehicles for the expression and reinforcement of these relationships. I now turn to the final section of this chapter and discuss what was learned through traditional teachings of the Elders regarding the significance of culture for Aboriginal women's sexual and overall health.

### *Significance of Culture for Aboriginal Women's Sexual & Overall Health*

In the final section of this chapter, I talk about the significance of culture for Aboriginal women's sexual health and wellness. In bringing together what I learned from the lived experiences of these Cree and Cree-Métis women and the stories and teachings of the women Elders, the goals and objectives of the research project were realized. The descriptions and insights that emerged from the work demonstrated the positive influences and impacts of culture on the sexual health and overall health of Cree and Cree-Métis women. Through reminding the reader of the concerns that guided the work with the women and the Elders, I summarize the ways in which this research was able to begin addressing these important issues. Further, these concluding discussions provide a brief overview of the research through identifying key findings that address the sexual health and overall health and wellness concerns of Cree and Cree-Métis women.

#### *Meeting the goals and objectives of the research*

As stated in the first chapter of this research, this study was composed of three inter-related phases. The second and central phase of the research was a gathering and analysis of the cervical cancer experiences and stories of five Cree and Cree-Métis women from across Northern Alberta. Their stories revealed that cervical cancer experience was only one incident that the women would identify as having impact on their health and illness. The first and third phases of the study were conducted in partnership with Cree and Cree-Métis Elders and their communities. Although structured individual interviews with Elders never took place, the development of an Indigenous research framework, based on principles of respect, reciprocity, and relationship building (and which necessarily followed the practices and protocols of the people involved in the research), supported the research objective to explore the significance of cultural teachings and knowledge for Cree and Cree-Métis women's sexual and overall health. This was achieved through a process that gathered the stories and teachings of the women Elders and showed through analysis how these validated and/or enhanced the descriptions provided by the Cree and Cree-Métis women of their illness experiences and provided insights into the ways in which cultural teachings and knowledge were manifest in the lived experiences of these women. Each of the questions that were used to guide the research, as listed in chapter one, are discussed in relation to the teachings of the Elders and how this validated and built upon the stories and lived experiences of the women.

> What cultural knowledge – traditions, norms, and teachings – are significant for the sexual health and overall health of Cree and Cree-Métis women? What are their implicit/explicit meanings for the sexual health of Cree and Cree-Métis women?

As demonstrated throughout chapters six and seven, cultural teachings and knowledge significant for the sexual health and overall health of Cree and Cree-Métis women are largely couched in notions and perceptions of identity. For the women involved in this research, this focus on Cree and Cree-Métis identity emerged despite the contradictory and sometimes hostile environments in which these women have been forced to survive. For example, the development and maintenance of culturally influenced female roles and relationships were shown to have emerged in the lives of the women and this suggests that they are integral to the development and maintenance of a positive sense of themselves as Cree or Cree-Métis females. Further, the stories and teachings of the Elders in relation to the sacredness and power of women, such as the traditional teachings regarding 'moon time' and childbirth, provided further insights into the contexts in which the women experience feelings of fear and apprehension with regards to Cree and Cree-Métis women's lived experiences of cervical cancer. This could then speak to the implicit aspects and meanings related to Cree and Cree-Métis culture and how these affect Cree and Cree-Métis women's sexual health and wellness.

> What cultural norms and values must be considered as significant and important in the development and delivery of sexual health programming and education for Cree and Cree-Métis women?

Relationships and the significance that these women placed on their relationships with others and the world around them emerged as key to Cree and Cree-Métis women's health and wellness. This was again demonstrated through the women's stories in relation to the ways in which they described the meanings of health and illness experience as embedded in their relationships with others. The work with the women Elders validated the importance that these women placed on their relationships with others and the world around them through identifying the many roles that these relationships have in contemporary Cree and Cree-Métis life, and through identifying these as the sources of cultural teachings and knowledge. This would include relationships to ancestors, Mother Earth, the spiritual realm, and ultimately the Creator. Although many of the Cree and Métis women who shared their stories and experiences in this research did not speak directly to these relationships in the same ways that the Elders did, the women did recognise the significance of these through the importance that they placed on cultural traditions and practices.

> What information is deemed significant to the particular concerns and issues of Cree and Cree-Métis women and their cervical health? What must be considered

> if the women are to use the information in ways that will affect their sexual health or choices regarding their sexual health?

Throughout the chapters that discuss Cree and Cree-Métis women's cervical cancer experiences, the women identified the lack of information and the willingness of health care service providers to share information regarding the development, diagnosis, and associated treatments and procedures of this disease as important to their illness experience. The stories and teachings of the Elders consistently revealed that a further understanding, on the part of academics, research, and health care service providers, is necessary in order to provide culturally appropriate and safe services and education to Aboriginal women. In particular, the importance of health care provider to follow basic principles of privacy and respect with regards to the common experiences of many Aboriginal women was cited as critical to the development of effective health education and services. Further, the capabilities of cultural teachings and knowledge to provide young women with a comprehensive understanding of their sexual and reproductive health, such as those teachings in relation to the menstrual cycles of the female, demonstrated the value of these traditional forms of knowledge and teachings in the development of Cree and Cree-Métis women's positive self-images as Indigenous females.

> What are viewed as the appropriate contexts in which to provide sexual health and cervical cancer education and information to Cree and Cree-Métis women?

The women all spoke to their concerns with regards to educating other young women, including their daughters and granddaughters, on topics that they believe to be important in relation to the development of cervical cancer and other illnesses. What they identified as an ongoing concern was that the common attitudes and demeanour of service providers do little to help women understand these issues and that the mistrust of health services and service providers is at least aggravated by the environment and bed side manner of health professionals. The stories of the Elders confirm that these experiences of Cree and Cree-Métis women are common and suggest that this situation is prevalent among Aboriginal peoples. Further, the recognition that there was an important need for this research to proceed in a culturally appropriate and safe manner – such as within the contexts of women's sexual and overall health – suggests that in order to learn and benefit from the sexual health and illness experiences of other Aboriginal women, health research with Aboriginal women needs to be carried out with similar care and under similar guidance. Moreover, the 'discovery' or more properly, the articulation of the ways in which cultural teachings and knowledge support the sexual health and wellness of Cree and Cree-Métis women was only made possible through the involvement of those peoples who are considered to be trusted and knowledgeable in these areas – Aboriginal Elders, traditional teachers, and knowledge holders.

> What cultural knowledge or traditional teachings do these Cree and Cree-Métis women utilize to maintain and improve their sexual health and overall health? How are these knowledge and teachings manifested in the cervical cancer experiences of the Cree and Cree-Métis women?

Specific cultural knowledge and teachings regarding the development of positive self-images and value for oneself as Cree and Métis individuals and women were shown to be present and emerging from the lived experiences described by these Cree and Cree-Métis women. This includes the significance of relationships, traditional practices and ceremony, self-sufficiency and independence, and the need to nurture all the dimensions of one's being, including the mental, the emotional, and the spiritual aspects of the individual. This was shown to have had significant impacts on the women's cervical cancer experiences and their overall health and wellness. The work with the women Elders validated these findings and built upon the descriptions shared by the Cree and Cree-Métis women, providing further insights into the significance of cultural teachings and knowledge on the health and wellness of Cree and Cree-Métis peoples. The Elders talked about the importance of nurturing the mind, body, and spirit and spoke to the healing that is necessary for Aboriginal peoples in order to achieve this. They also talked about the role of ceremony in nurturing the spiritual well being of individuals and identified two kinds of illness – physical and spiritual. The work of Goudreau (2006) refers to the significance of spirituality in the lives of Aboriginal peoples when she states,

> *Of the four elements of being... the spiritual element was discussed most frequently by the participants. This is no surprise since spirituality is central to Aboriginal people and an integral part of every aspect of daily life. From the Aboriginal perspective, spiritual needs are every bit as important as eating and breathing: It is what one participant described as sustenance. She stated, "It [the drumming] is as important as air to me" (p. 97).*

> How do the Cree and Cree-Métis Elders, teachers, and traditional knowledge holders interpret the stories of Cree and Cree-Métis women with respect to cultural knowledge and teachings? What language is used to name and describe the experiences of Cree and Cree-Métis women?

Although the Elders were not involved in the direct analysis of the data from the women's stories, they overwhelmingly identified the same concerns and areas of priority that these women had talked about regarding their health and illness experiences. As demonstrated throughout this chapter, the stories of the Elders and the cultural teachings and knowledge that emerged through these stories validated and built upon the stories of lived experiences of these Cree and Cree-Métis women. The Elders would, in fact, often use the same words as the women in talking about the significance of health and illness experiences from Cree and Cree-Métis perspectives and from within Cree and Cree-Métis lived realities. This included words like "strength" and "power" in talking about mental dimensions of health and phrases such as "the knowing" in relation to health and healing. Further, the women talked about the loss of culture and language as impacting their health and wellness. This was also pointed out by the Elders and was referred to as "the message" that is embedded within the stories and traditional teachings of ancestors. The significance of culture for the health and wellness of Cree and Cree-Métis women emerged from their stories in terms that connected with perceptions of a positive self-image or Cree and Cree-Métis identity and as necessary tools for healthful living and living well.

This research explored the role of cultural norms, teachings, and traditions as integral to the sexual health and overall health of Cree and Cree-Métis women in a context of cervical cancer and cervical cytology screening. A major outcome of this study was to provide healthcare service providers, researchers, program developers, policy makers, and in particular, Northern Alberta communities with a description of the cervical cancer experiences of Cree and Cree-Métis women. Additionally, insights were drawn regarding the culturally specific influences that enhance and support the sexual health and overall health of Cree and Cree-Métis women. Through the development of an Indigenous research framework, extraordinary opportunities were created for the researcher to come together with Cree and Cree-Métis women and women Elders in order to learn about traditional teachings and knowledge that were shown to influence and impact the sexual health and overall health of Cree and Cree-Métis women. The significance of these influences and impacts are further discussed in the final chapter of this research as being important for the development of culturally appropriate and safe health research, health education, and health service delivery for Aboriginal women, including the Cree and Cree-Métis of Northern Alberta.

# CHAPTER EIGHT: BRINGING THE TEACHINGS & INSIGHTS TOGETHER

> *As we discover the strengths in our culture, we will begin to discover our own strength. Several participants stated that when they participated in Aboriginal cultural traditions such as drumming, they became stronger and able to tackle anything. With the strength of our culture, the hurdles in our lives become easier to handle as we learn to put things in perspective and not worry about things that do not matter. We also learn to speak up for ourselves as many of us have found our voices. (Goudreau, 2006, p. 108)*

The purpose of this final chapter is to bring together what was learned in doing this research with Northern Alberta Cree and Cree-Métis peoples. I begin with a short discussion on the ways in which the many insights that were gained may contribute to the development of future health research, health education, and service delivery for Aboriginal women and their communities. Then, I talk about several of the challenges that were overcome in carrying out this study. Next, I summarize my conclusions with regards to the significance of cultural teachings and knowledge in the development of Indigenous female identities, especially as this relates to sexual health. In the final section of this final chapter, I will address the ways in which I believe the development and conduct of this research process from within an Indigenous research framework worked to dissipate the current negative orientations and views that are held of Aboriginal women and their sexual health. This includes the implications of these for Aboriginal women and their communities, myself as an Indigenous researcher and health care educator and service provider, and the greater community of health research, health education, and service delivery.

Health research, health education, and service delivery for Aboriginal women and their communities in relation to this research recognises culturally informed knowledge and its impacts on the sexual health and wellness of Aboriginal women and is built upon the foundations that Aboriginal cultural teachings and knowledge are integral to the ways in which Aboriginal women experience health and illness.

## *Significance of the Research*

The 1996 *Royal Commission on Aboriginal Peoples* emphasized that meeting the future needs of Aboriginal peoples requires evidenced-based information on the most pressing health concerns and challenges faced by Aboriginal peoples (1996a). As well, health policy has been cited as having little available research and information that acknowledges the significance of cultural norms and traditions as integral to the health and wellness of Aboriginal peoples and communities (Dion Stout & Kipling, 1998; Royal Commission on Aboriginal Peoples, 1996a). I have also noted throughout this document that health research, health education, and service delivery have limited resources to draw upon in relation to the development of culturally appropriate and sensitive care for Aboriginal women with specific regards to their sexual health. For the generations of Aboriginal peoples who have been unable to fully benefit from access to their own cultural teachings and knowledge, this project represents one opportunity to 'reposition' ourselves and uncover or reclaim some of that knowledge through the insights that were gained in working with Cree and Cree-Métis women, Elders, and communities. Additionally, this study shows that relationship building engenders trust which, in turn, supports women, Elders, and communities to be involved in discussing improved health.

Anticipated and desired outcomes of this project largely fall within three main areas: 1) the discovery of new insights that support and lead to renewed views of Aboriginal women and their sexual health, 2) the translation and utilization of culturally informed knowledge for Aboriginal women in relation to their sexual health and overall health, 3) the value of consulting Elders, traditional teachers, knowledge holders and community members from the population you wish to engage in the research, and 4) the development of new resource materials for health education and program development purposes within public, First Nations, and Métis health service delivery and health education systems.

1) A move away from current pathologizing views of Aboriginal women in relation to their cervical and sexual health was a primary desired outcome of this research. The discovery of new insights that support and lead to renewed views of Aboriginal women and their sexual health and overall health is a first important step toward health research, health service delivery, and health education development that rejects current approaches and which develops future health education and delivery that is culturally informed and appropriate. This may be suggested to have potential future impacts on cervical cancer incidences and cervical cancer deaths among Aboriginal women as the processes of this research and ongoing dialogue with Aboriginal Elders, teachers, and knowledge holders worked to provide a solid foundation for future work in the area of access to such

culturally informed knowledge. Therefore, building upon what was learnt during this project may lead to the development of health education and services for Aboriginal women and their communities that is based in the lived experiences and cultural realities of a particular group or nation.

2) The translation and utilization of culturally informed knowledge for Aboriginal women in relation to their cervical and sexual health may lead to renewed understandings of Northern Cree and Cree-Métis women and their health. Through the clear and appropriate articulation of those factors that these women view as integral or important to their sexual health, the complexities of Aboriginal women's sexuality and sexual health from within traditional perspectives may be translated into usable forms of knowledge and information. Specifically, health education and service delivery for Aboriginal women and communities has the real potential to develop such future frameworks based in Aboriginal conceptualizations of female sexuality and sexual health.

3) The acknowledgement that improving women's sexual and overall health in these populations requires sufficient time and energy to be invested in order to engage in the respectful processes, such as relationship building, that the health researcher must engage in to develop health programming that is acceptable to the women, Elders, and community members involved.

4) The development of new resource materials for health education and program development purposes within public, First Nations, and Métis health service delivery and health education systems. The data that is available through this research may lead to new research on Aboriginal health that recognizes explicitly the multiple complexities of Aboriginal cultures for Aboriginal health and wellness. This becomes possible through the guidance and teachings of Elders, teachers, and traditional knowledge holders who are able to provide the experiential and vital basis of the significance of cultural teachings and

knowledge for the health and wellness of Aboriginal peoples. The creation of such new resource materials may then reflect the meanings of health and illness experiences for Aboriginal peoples through their potential re-connection to the cultural norms, traditions, and practices of Aboriginal peoples and communities.

In closing this section of the chapter, I suggest what I consider to be of potential significance for Nursing in relation to the sexual health and wellness of Aboriginal women and their communities. Nurses, involved in the direct development and delivery of care to many Aboriginal women may benefit from a recognition of the following:

1) Recognising the sexual health concerns of Aboriginal women requires an acknowledgement of the significance of culture for the health and wellness of these populations. This can then work to ensure that the approach to these issues and concerns is culturally safe and appropriate to these populations. Such an approach is then able to provide the related sexual health assessments and interventions needed in a respectful and acceptable manner.
2) Further understanding of culturally appropriate and safe care, on the part of many health service providers, is required to ensure that the sexual health needs and concerns of Aboriginal women are addressed – in particular, service providers need to be aware of the pain and fear that is associated with receiving care regarding sexual health concerns and need to take the time to provide information regarding diagnosis, treatments, procedures, and disease development and prognosis.
3) Nurses, as primary care providers to Aboriginal women need to recognise that many of the assumptions that are commonly held regarding Aboriginal peoples and their sexual health are either misguided or poorly understood; therefore, unless one has specific knowledge and expertise in these areas – working with Aboriginal women in relation to their sexual health and sexual health concerns requires an openness and a willingness to share and learn.

4) Nurses need to acknowledge and respect that Aboriginal women, similar to all women of society, are the experts on their own health and wellness, and that this expertise or knowledge has developed through their own lived experiences.
5) The urgent need for curriculum development for the health professions that includes and addresses Indigenous approaches to health and healing. Cultural safety must be acted upon by curriculum specialists and not just relegated to a nice-to-know item. In addition, I suggest that based on current literature and the findings of this study that Northern Cree Elders, women, and their communities do not want to be assimilated into the health programming for immigrants and other Canadian women. These programs do not meet the culturally specific and sensitive requirements that are needed to decrease the burden of this and other diseases within the Indigenous population.

### *Meeting the Challenges of Indigenous Research in Working from Within Western Intellectual Research Frameworks*

Working from within western intellectual research frameworks as an Indigenous woman, community member, and researcher involved many challenges. Some of these included making sense of what is taught from a western perspective to the realities of working with Aboriginal peoples and their communities. This included working from within the restrictive processes that are pervasive within our academic institutions and the research arena. The majority of these challenges are faced on an almost daily basis during my work and the work of other Indigenous colleagues. I talk here about some of these challenges in relation to what was learned during this research and how this may be viewed as significance for the work towards the improved health and wellness of Aboriginal women.

The research timelines set by the Faculty of Graduate Studies & Research and other national funding bodies do not include the preparation work to build the trusting relationship mentioned frequently throughout this research. This includes carrying out the research and the ethical responsibilities of Indigenous researchers to return what was learnt from knowledge enquiry endeavours and research to the communities involved in the process. As well, this time-requirement needs to recognise, that I, as an Indigenous researcher and community member am responsible for the research for my lifetime and how it will be received and affect communities. While I did not have difficulty receiving ethical clearance for my study, many of the items I had to respond to, did not fit with the practices and protocols of the Cree and Cree-Métis peoples involved in the study.

As well, making sense of what is taught from western perspectives in relation to the lived realities of Aboriginal peoples was alluded to throughout the first sections of this research that identified the complex nature of Aboriginal women's health and illness experiences in today's environment. I stated that this research would necessarily acknowledge these variances in the historical, social, and political environment of Aboriginal woman. One important way for the research to do this was to take the time and spend the energy that was required to carry out the activities of the research in ways that would respect the lives and traditions of the people involved in the research. What I found in trying to achieve this was that the restrictive processes and imposed stereotypes of Aboriginal women and their health required that I remain keenly aware of the ways in which this research could impose the same restrictions and stereotypes on the Cree and Cree-Métis women, Elders, and communities involved in this study.

Further, some of these restrictive processes were intimately tied to the stereotypical attitudes and ideas about Aboriginal women, Elders, and their communities. As mentioned previously, carrying out this research led me to further understandings of the ways in which Indigenous knowledge systems work to support the development of positive Indigenous female identities. This ultimately meant that acknowledging community members, such as Elders, as educators would be required during this research. However, many of the disciplines that I found myself involved with were not as willing to make this acknowledgement as I was. This has become clear to me through the ways in which the expenditure of funds to bring these traditional teachers and knowledge holders to the university to work with students or participate in the learning activities organized by other Indigenous academics is always questioned in relation to its educational purposes and values. Although these restrictive and prohibitive circumstances may be viewed by non-Indigenous faculty members and educators as improving, those of us working from the outside are constantly aware of the persistent need to justify our educational objectives. In relation to my own research, I came to realise the expertise and sources of the knowledge that I relied upon may come into question.

One of my concerns was related to whether the findings were sound in stating that the stories and teachings of the Elders did in fact build on the work with the women in the ways that I had described them. For instance, did the work with the Cree and Cree-Métis Elders validate the lived experiences and concerns of these Cree and Cree-Métis women simply because the Elders involved in the research possessed similar orientations to the world? In reflecting upon this, I realized that this work relied on descriptions of Cree and Cree-Métis women's lived experiences as much as possible because I sensed that this was one way to validate my own interpretations of the data. I found support for my assumptions in the work of Weber-Pillwax (2003) where she states, "descriptions are crucial…because it is impossible to rely totally on interpretations to convey meaning accurately" (p. 31). Further, similar cultural orientations of the Elders (to that of the women) were in fact the reason that their stories and teachings could build upon the stories and experiences of the women; otherwise, it would not have mattered if the Elders were also from Northern Alberta Cree and Métis communities. In the end, this worked to ensure that the orientations and cultural teachings of these women Elders would be valid in examining the stories and experiences of these women. Moreover, my interpretations of this data were based on the same assumptions that the participants possessed. For example, similar to the participants involved in the research, I understood that cultural teachings and knowledge emanate from sources outside of ourselves. This understanding would, in fact, work to assure me that the data from the women Elders would provide deeper and more meaningful insights and understandings into the women's health and illness experiences. Deeper and more meaningful insights into the sexual health and wellness of the Cree and Cree-Métis women involved in this research include the intimate relationships and inter-relationships that were shown to exist between the cultural teachings and knowledge of the Cree and Cree-Métis of Northern Alberta and the development of positive female Indigenous identities. This is discussed in the following section of this chapter.

### *Cultural Teachings and Knowledge as Key to Indigenous Well Being*

> *It has been said that the Cree people, for example, do not have written records and so our history is not available to us. Although that is not true, it is true that many of our people do not have access or understanding of the language in which such history and knowledge is embedded and through which they are passed on to following generations. The education processes that the governments and the churches enforced in the period of the early 1800's and right up to the 1950's were such that the loss of languages and cultures for the people were inevitable. The impact of such loss on identity and wellness of individuals and communities has been referred to as a holocaust. For Aboriginal peoples and their health, the effects continue into the present. The need for Aboriginal knowledge and teachings to initiate and guide health service delivery and education is clear to Elders, leaders, and communities in general. (CURA Research Grant Application, Weber-Pillwax, 2005)*

The analyses of Cree and Cree-Métis women's health and illness experiences in this research provided evidence of the integral role that Cree and Cree-Métis cultural teachings and knowledge play in the development of a positive female self-image. Forced to survive in an environment that is fraught with social, economic, and political challenges, the women who participated in this study alluded to the value and important role that cultural teachings and knowledge possess in relation to their overall health and wellness. Reflected in the women's stories through their descriptions of how they have come to value themselves as Cree and Cree-Métis women, these aspects of Indigenous identity formation may be viewed as key to the health and wellness of Indigenous women and individuals. Within this section of the chapter, I talk about how I came to view the loss of language and culture as being a significant determinant of the poor sexual health outcomes that these women experienced.

The abilities of cultural teachings and knowledge to provide the base for a 'sense' of oneself as an Cree and/or Cree-Métis woman, mother, and individual were presented in Chapter six and seven. Further, the analyses and descriptions of the data demonstrated their long-term impacts on the personal and collective health of these women and their families. For example, the inabilities of the female participants and myself, as the researcher, to speak our Native languages revealed the complex historical and political nature of the challenges that are faced and experienced by many Aboriginal peoples to learn and retain the cultural teachings and knowledge of their ancestors. The trial for many young Aboriginal women in these instances then becomes one of access to cultural teachings and knowledge that are embedded within the first languages of the Peoples, such as the Cree and Cree-Métis of Northern Alberta. The processes and findings of this research provided evidence of the long-term impacts on the personal and collective health of Cree and Cree-Métis women in relation to the loss of language and culture in two distinct and significant ways – 1) through an examination of the processes of the research to access the Cree data, and 2) through the discussion of research findings of the data analyses of the Cree and Cree-Métis female participants and the Elder women in relation to Cree and Cree-Métis female identities.

In chapter six, I stated that throughout the text, health and healing have been presented as inseparable and synonymous aspects of Aboriginal wellness. In the previous chapter, the Elders talked about healing as 'a message' that is found within the stories of their ancestors. In fact, the Elders spent a great deal of time talking about healing and its relationships to wellness. The contexts of these discussions included the need for appropriate understandings of traditional medicines in relation to their healing powers, particular ceremonies and their healing powers to treat different illnesses, and the relationships between spiritual healing and wellness. These relationships between healing and wellness were seen as being grounded in basic principles of human existence and the spiritual lessons that are received through traditional ceremonial activities. Alice Reid spoke to these basic principles and referred to the spiritual lessons or teachings of Aboriginal peoples as necessary to bring about healing. She stated,

> *We didn't have churches or buildings to be in. We had our tepees and our lodges and our sweats and we had those things dismantled. But they weren't permanent structures. We didn't have permanent structures. We had to live on the land because there wasn't any place else to live. So I learned some of my teachings, not just from my father, but from other teachers across Canada, the United States, and South America and I've learned from all those teachers some very basic principles. Number one – the Creator is the Creator. Number two – we walk many different paths, but we still are all connected to the Creator.*

Couched in issues of identity, an area of priority – traditional teachings and knowledge impact how these women care for themselves – emerged from the data as elements of a positive Cree and/or Cree-Métis female identity that the women have been able to retain. Despite clarity, on the part of the female participants and myself, as the researcher, in relation to the meanings that are embedded within the teachings, Cree and Cree-Métis cultural knowledge and teachings were shown to form the basis for these women's positive self-images as Cree and Cree-Métis females.

Further, the research findings revealed that these women allude to and convey the 'desires' and 'compelling needs' of Aboriginal peoples to learn and understand the traditional teachings and knowledge of their ancestors. Similarly, the experiences of the women Elders in teaching appropriate understandings of cultural teachings and knowledge and myself, as the researcher, in learning and retaining appropriate understandings of cultural teachings and knowledge may also be described as working to overcome challenges. While I, as the researcher, struggled to access some of the teachings and knowledge that were embedded in the Cree data, descriptions of the women Elder's experiences also revealed that they struggled to appropriately convey the messages of cultural teachings and knowledge that are embedded within Native languages into forms that non-Cree speakers, such as myself, are then able to understand. For example, during the one-day session with the Elders, Isabel Auger stated:

> *The language. The language. You have to have the language to be able to listen.*

As well, the abilities of the research findings from the data with the women Elders to validate and build upon the data from the women provides evidence of the potential significant impacts of cultural teachings and knowledge on the personal and collective health of Cree and Cree-Métis women and their communities. Indeed and from within these contexts, the ability of the Elder's stories and the cultural teachings and knowledge held within the stories to validate the lived experiences of the women in relation to Cree and Cree-Métis female identities provides evidence of their significance for the health and wellness of Aboriginal peoples. What I have tried to convey in this work is that the capabilities and possibilities of the Elder's traditional teachings and knowledge to provide further insight into the health and illness experiences of the Cree and Cree-Métis females involved in this project is significant. This is, in fact, already known and already understood by many Aboriginal peoples from across Canada. I believe, however, that this work provides evidence of the significance of cultural teachings and knowledge for the health and wellness of the individual women who participated in this study. I also believe that this work provides some indication of the potential of Indigenous cultural teachings and knowledge to possess many of the key understandings that are necessary to the improved health and lives of Indigenous peoples. At the risk of oversimplifying the very complex nature of the Indigenous world and the lived realities of Indigenous women across the globe, it behoves me to say that the articulated possibilities of the 'evidence' that is presented in this work suggest to me the sound indication that further research in this area could one day potentially lead to benefits for the health of Indigenous women. Benefits that could include change to the ways in which sexual health research and health education and services are delivered to the larger populations of Indigenous women and their communities.

### *Closing*

This study carried out health research with Northern Alberta Cree and Cree-Métis women, Elders, and communities that specifically involved those areas of health that delve into the private aspects of individual lives, crossing long-established boundaries of personal as well cultural construction. The process of building a research community of trust under the guidance and direction of women Elders and the process of working with peer researchers to access the knowledge embedded in the data collections was brought forward. The significance of language and culture was explained in relation to the research itself, demonstrating their long-term impacts on personal and collective health. Potential implications that address the health and education aspects of Aboriginal women's wellness were also discussed. The final section provides closing thoughts on the research process as I experienced it. First, this identifies the significance and impacts of culture on the health and wellness of Aboriginal peoples as critical to improved health and wellness, the optimal maintenance of health and wellness, and positive health outcomes. As well, this underscores the need for health research and service delivery to recognise traditional teachers and knowledge holders as having expert knowledge of women's health and wellness. Further, this suggests that health research is missing significant opportunities to create new knowledge and develop important insights in relation to sexual health and wellness, women's health and wellness, and traditional medicine and treatments. Finally, the significance of cultural teachings and knowledge for the health and wellness of Aboriginal women reinforces the need for future health research and service delivery to move away from deficit models of care toward frameworks that recognise and emphasize the inherent knowledge and vitality of Aboriginal peoples.

The ability of policy to actually reach the frontline staff within hospitals and community health centres largely rests upon the health region or authority that takes the time and invests the money that is required to have these skills taught to Nurses and service providers. Therefore, health policy and Nursing policy must address several issues and concerns if there are to be improvements to the education and services that are provided to Aboriginal women in relation to cervical cancer and cervical cytology screening. First and probably foremost, in order to identify those aspects of Aboriginal culture(s) that are specific and integral to the sexual health of Aboriginal women, health and nursing research must conduct culturally specific and applicable research if the research is to be of benefit and work toward the improved health of Aboriginal peoples. The development and implementation of this research from within an Indigenous framework has been shown to produce reliable and relevant findings. Second, Aboriginal researchers should lead or direct this type of research, for several important reasons. 1) As identified throughout this research, this is a highly sensitive subject for Aboriginal women and relationships must already be in place if the research is to result in valuable insights and reliable, useful results. 2) Aboriginal researchers already possess personal and experiential knowledge of Aboriginal culture and its inter-relationship and relationships to the ways in which Aboriginal women think and act. 3) The need to develop theory of the ways in which Aboriginal women use knowledge, such as the education that is provided in relation to cervical cytology screening, is already available as many Aboriginal researchers already possess and have as available this kind of theory. This has been demonstrated through the stories and teachings of the women Elders who provided concrete information and knowledge regarding the treatment and care of Aboriginal women in relation to their sexual and overall health and illness experiences.

Considering the impacts that cultural teachings and knowledge were shown to have on the health and wellness of the Cree and Cree-Métis women who participated in this study, health researchers need to develop and conduct future research that incorporates cultural perspectives within their research frameworks. In addition to recognising the knowledge and insights of community members regarding health and wellness, researchers need to acknowledge that this knowledge includes learning from our women, men, youth, and Elders. In the area of Aboriginal peoples' sexual health research, this recognition is perhaps even more crucial with the realisation that cultural teachings and knowledge encompass information and lessons that are embedded in an Aboriginal individual's relationships with others and the world around them.

Screening research with Indigenous populations will likely increase due to the recent advances in the prevention of cervical cancer, such as the HPV vaccine. Without further understanding of the knowledge that Indigenous women do possess, such as this research that draws attention to the impacts of culture on the sexual health and illness experiences of Cree and Cree-Métis women, it is likely that sexual health and screening research will continue to focus on 'deficit model' approaches and the lack of knowledge or neglect of Indigenous women in relation to addressing cervical cancer prevention and concerns. As demonstrated through the literature review of current approaches to sexual health and cervical health research with Indigenous women, research in these areas of concern with Indigenous women will likely continue to produce poor results unless future research moves away from pathologizing the lives and experiences of Indigenous populations towards the liberation of individuals and communities.

As an Indigenous researcher, my responsibilities towards the people and communities involved in this work did not end upon the completion of this document. In fact, I still have much to do in order to meet my obligations towards all my relationships. This includes following the strategies that I have planned to take the work back to communities and community members. Further, this project was likely only the first stage of my work in relation to the impacts of culture on the sexual health and wellness of Aboriginal women. Moreover, the relationships that were developed during this project have come to be a valuable source of support for me. Building this support through working with Aboriginal women, Elders, and communities will provide the foundation for future research in this area.

The experience of developing and carrying out this research represents a turning point in my professional career and personal life. What I was able to learn through developing relationships with these women, Elders, and communities will remain at the forefront of future research endeavours and work with Indigenous peoples and will surely enhance the teaching that I do with my own children and grandchildren. I have always believed that learning more about Aboriginal peoples would help me to gain further acceptance of peoples from other cultures. As I take this experience back to the front-lines of nursing education and service delivery, I am confident in saying that I have developed a deeper understanding of 'the ways in which we view people significantly determines the choices that we offer them'.

Trusting what I have learnt as an Aboriginal/Indigenous person, I knew that the lived experience of an individual is not only considered to be an important process of learning, but it is also viewed as a significant form of knowledge or as a unit of knowledge in and of itself. This understanding formed the rationale for what I felt was a culturally respectful approach and use of the stories from the data with the women Elders. In the end, I decided to approach writing these sections using the Elder's words and stories as a way to validate and build upon what the women identified as significant to their health and illness. Rather, I chose not to analyse the data from the women Elders for thematic content or for the purposes of categorizing cultural teachings and knowledge into a subset of western ideas and concepts. In this way, I believe that I was able to exercise and maintain a culturally appropriate and respectful approach towards the cultural teachings and knowledge that I had learned from these women Elders. Throughout this process and that which I have tried to reflect in the final outcomes that are presented within this document, my own cultural knowledge (or worldview) played a key role in my decisions. Additionally, this rationale and approach to all that I had learnt in working with the Elder women made it somewhat easier to identify what was directly applicable to the work with the women and what was part of my greater lifelong learning as an Aboriginal/Indigenous person. What this essentially means is that for some of the people who choose to read this work, such as other Indigenous researchers and scholars, is that they will likely recognise the deeper and often multi-layered meanings and cultural concepts that are embedded in the stories of the Elder women because they have earned this knowledge through their own life experiences as Indigenous peoples.

This research and its framework represent one example of a culturally appropriate and respectful research approach in which to engage and learn of the sexual health and illness experiences of Aboriginal women. Through adhering to the protocols of the peoples and communities involved in the study, I engaged in activities and processes that followed Indigenous principles of respect, reciprocity, and relationship building. Following these principles worked to create a culturally appropriate and safe environment from which to share potentially stigmatizing information, on the part of the women and Elders who shared their lived experiences, and in which the women Elders could then engage with one another and the researcher for the purposes of sharing cultural teachings and knowledge. Based in processes that focused on the building of relationships, rather than my learning as the researcher, the knowledge that was gained through engaging with the women and Elders contributed to the rich and meaningful sources of the data that were gathered during this research.

This research was conducted with Cree and Cree-Métis women, Elders, and communities from across Northern Alberta. The sexual health of Cree and Cree-Métis women was examined through gathering the stories of five women in relation to their experiences with cervical cancer. Thematic analysis of these experiences revealed that feelings of pain, fear, and anxiety were associated with diagnoses, treatments, and procedures related to the care of cervical cancer. The attitudes of service providers and the lack of information given to the women by health service providers were shown to be a source of frustration for these Cree and Cree-Métis women and contributed to feelings of fear and mistrust towards health service providers and health service delivery.

Within the stories of these women, it was noted that they spoke about their cervical cancer illness as only one incident that had affected their health and wellness. What emerged from their stories were four areas of priority that were seen as affecting their health and wellness. This included mental, emotional, and spiritual dimensions of health, abuse and violence, the loss of culture and language, and cultural teachings and knowledge. These four areas of priority were shown to influence the health and illness experiences of these Cree and Cree-Métis women and were demonstrated to have impacts on the ways in which they care for their health and wellness.

Additionally, the women's stories would demonstrate that Cree ways were manifest in their lived experiences as cultural knowledge and teachings would be shown to provide the women with positive self-images, feelings of self-worth, and a sense of oneself as a Cree and Cree-Métis female. Further, cultural teachings and knowledge were viewed as the tools and lessons that lead to healthy living, which includes a sense of value for oneself as a Cree and Cree-Métis woman was expressed as possessing strength, independence, self sufficiency. Through working with the women Elders, I would find that their stories and teachings contained traditional teachings and knowledge that would validate the experiences of Cree and Cree-Métis women. What I would learn from the Elders would also build on current knowledge and understandings of Aboriginal women and their sexual health and overall wellness.

Throughout this research, relationships have been shown to play a central role in how Cree and Cree-Métis women come to know and understand their experiences. For the women involved in this research, this would include how they would come to care for their emotional, mental and spiritual well being, the support that they offered others and received from others, and what they would learn from others in relation to female roles, self worth, and values. The different forms of abuse that these women have experienced would also be shown to have important impacts on their health and wellness. The stories and cultural teachings that the Elders provided would recognise these experiences as detrimental to the health and wellness of individuals and provide teachings and lessons that described the healing necessary to address these issues and concerns. They would also recognise the impacts of these through their stories that identified the significance of the loss of language and cultural knowledge for the health and healing of Cree and Cree-Métis women and communities. Although they would attach cultural meanings to these losses that were embedded in the identities of Cree and Cree-Métis peoples, their discussion of cultural teachings and knowledge would demonstrate that the rules and constructs for positive female identities remain available to Cree and Cree-Métis women through the wisdom and knowledge of ancestors, the spiritual realm, Mother Earth, and ultimately the Creator.

## References

Aboriginal Cancer Control Strategy Planning Committee. (1999). *Guiding principles*. Unpublished paper. Edmonton, AB: Aboriginal Cancer Control Strategy Board.

Aboriginal Health. (1992). *Aboriginal health in Canada*. Ottawa, ON: Minister of Supply and Services Canada.

Aboriginal Nurses Association. (1996). *HIV/AIDS and its impact on Aboriginal women in Canada.* Ottawa, ON: Department of Health Canada.

Aboriginal Nurses Association of Canada & Planned Parenthood Federation of Canada. (2002). *Finding our way: A sexual and reproductive health sourcebook for Aboriginal communities.* Ottawa, ON: Aboriginal Nurses Association of Canada.

Absolon, K. (1994). Building health from the Medicine Wheel: Aboriginal program development. Paper presented at Native Physicians Association Meeting, Winnipeg, MB, March 6-8.

Alberta Cancer Board. (2001). *Lifestyle series teaching packages for health professionals in Alberta's regional health authorities.* Retrieved April 15, 2006 from http://www.cancerboard.ab.ca/cancer/cancer_online.html

Alberta Cancer Registry. (2007). *New cancer cases by site, Alberta.* Division of Population Health and Information: The Alberta Cancer Board.

Alberta Health. (1995). *Strengthening the circle: What Aboriginals say about their health.* Edmonton, AB: Author.

Alliance for Cervical Cancer Prevention. (2004). *Cervical cancer prevention: Issues in depth.* Seattle, WA: Alliance for Cervical Cancer Prevention.

Alberta Health and Wellness. (2004). *Sexually transmitted infections (STI) surveillance report: Alberta – 1998 to 2002*. Edmonton, AB: Alberta Health and Wellness. Available online: http://www.health.gov.ab.ca

Alvi, R. A. (1999). *Breast, cervical and colorectal cancer survival rates for northern Saskatchewan residents and First Nations.* Unpublished Master's Thesis, University of Saskatchewan, Regina, SK.

Amnesty International. (2004). *Stolen sisters: A human rights response to discrimination and violence against Indigenous women in Canada.* Ottawa, ON: Amnesty International.

Anderson, K. (2000). *A recognition of being: Reconstructing Native womanhood.* Toronto, ON: Sumach Press.

Asetoyer, C., Cronk, K., & Hewakapuge, S. (2003). *Indigenous women's health book, within the sacred circle: Reproductive rights, environmental health, traditional herbs and remedies.* Lake Andes, SD: Native American Women's Health Education Resource Center.

Atkinson, J. (2000). Lifting the Blankets. Unpublished doctoral dissertation. Queensland University of Technology, Brisbane, Australia.

Atkinson, J. V., Graham, J. P., Pettit, G., & Lewis, L. (2002). Broadening the focus of research into the health of Indigenous Australians. *The Medical Journal of Australia 177*(6), 286-287. Retrieved September 3, 2005, from http://www.mja.com.au/public/issues/177_06_160902/atk10444_fm.html

Auger, J. (2005). *Sexual health practices among First Nations adults and the need for culturally appropriate STI/HIV education.* Unpublished manuscript from First Nations Regional Longitudinal Health Survey (RHS) 2002/03. Ottawa, ON: First Nations Centre.

Band, P., Deschamps, M., Hislop, T., & Clark, H. (1995). *Cervical cancer mortality and screening Native Indian women of British Columbia.* Paper presented at the North American Association of Central Cancer Registries Conference, San Francisco, CA.

Band, P., Gallagher, R., Threlfall, W., Hislop, T., Deschamps, M., & Smith, J. (1992). Rate of death from cervical cancer among native Indian women in British Columbia. *Canadian Medical Association Journal, 147*(12), 1802-1804.

Bartlett J. G. (2005). Health and well-being for Métis women in Manitoba: Developing indicators and measures. *Canadian Journal of Public Health, 96*(Supplement 1), 22-27.

Battiste, M., & Youngblood Henderson, J. (2000). *Protecting Indigenous knowledge and heritage.* Saskatoon, SK: Purich Publishing.

BC Aboriginal HIV/AIDS Task Force. (1999). *The red road: Pathways to wholeness. An Aboriginal strategy for HIV and AIDS in BC.* Vancouver, BC: BC Aboriginal HIV/AIDS Task Force. Available Online: http://www.healthservices.gov.ab.ca/cpa/publications/red-road.pdf

Bennett, M. (2005). *Annotated bibliography of Aboriginal women's health and healing research.* Vancouver, BC: Aboriginal Women's Health and Healing Research Group.

Benoit, C., Carroll, D., & Chaudhry, M. (2003). In search of a healing place: Aboriginal women in Vancouver's downtown eastside. *Social Science and Medicine, 56*(4), 821-833.

Benoit, C., Carroll, D., & Kaufert, P. (2001). *Moving in the right direction? Regionalizing maternity care services in British Columbia, Canada.* Toronto, ON: The National Network on Environments and Women's Health, a Centre of Excellence on Women's Health, York University.

Bent, K. (2004). *Anishinaabe ik-we mino-aie-win. Aboriginal women's health issues: A holistic perspective on wellness.* Winnipeg, MB: Prairie Women's Centre of Excellence. Available Online: http://www.pwhce.ca/pdf/abWoHealthBentFull.pdf

Bent, K., Josephson, W., & Kelly, B. (2004). Effects of an Aboriginal cultural enrichment program on adolescent mothers' self-perceptions. *First Peoples Child & Family Review,* 1(1), 83-100.

Blaut, J. (1993). *The colonizer's model of the world.* New York: The Guilford Press.

Bobak, I., Jensen, M., & Zalar, M. (1989). *Maternity and gynecological care: The nurse and the family.* St. Louis, MO: CV Mosby Company.

Bosch, F., Lorincz, A., Munoz, N., Meijer, C., & Shah, K. (2002). The causal relationship between Human Papillomavirus and cervical cancer. *Journal of Clinical Pathology, 55*(4), 244-265.

Bottorff, J., Balneaves, L., Sent, L., Grewal, S., & Browne, A. (2005). Cervical cancer screening in ethnocultural groups: Case studies in women-centered care. *Women's Health, 33*(3), 29-46.

Bowden, F., Tabrizi, S., Paterson, B., Garland, S., & Fairley, C. (1998). Determination of genital Human Papillomavirus genotypes in women in Northern Australia using a novel, self-administered. *International Journal of Gynecological Cancer,* 8(6), 471-475.

Braveheart-Jordan, M., & DeBruyn, L. (2005). So she may walk in balance: Integrating the impact of historical trauma in the treatment of Native American Indian women. In J. Adleman & G.M. Enguidanos (Eds.), *Racism in the lives of women: Testimony, theory and guides to antiracist practice.* New York: Haworth Press.

Brentjens, M., Yeung-Yue, K., Lee, P., & Tyring, S. (2002). Human Papillomavirus: A review. *Dermatologic Clinics, 20*(2), 315-331.

British Columbia Ministry of Health. (2000). *Report on the action forum on Aboriginal women's health and addiction services.* Victoria, BC: British Columbia Ministry of Health.

British Columbia Vital Statistics Agency (BCVSA) for Medical Services Branch, Health Canada. (1999). *Status Indian trend analysis by four areas: Over the period 1987 to 1997.* Vancouver, BC: Health Canada.

Browne, A., & Fiske, J. (2001). First Nations women's encounters with mainstream health care services. *Western Journal of Nursing Research, 23*(2), 126-147.

Browne, A., Fiske, J., & Thomas, G. (2000). *First Nations women's encounters with mainstream health care services & systems.* Vancouver, BC: British Columbia Centre of Excellence for Women's Health.

Browne, A., & Smye, V. (2002). A post-colonial analysis of health care discourses addressing Aboriginal women. *Nurse Researcher, 9*(3), 28-41.

Brownridge, D. A. (2003). Male partner violence against Aboriginal women in Canada - An empirical analysis. *Journal of Interpersonal Violence, 18*(1), 65-83.

Brunen, L. (2000). *Aboriginal women with addictions: A discussion paper on triple marginalization in the health care system.* Prince George, BC: Northern

Secretariat of the BC Centre of Excellence for Women's Health. Available Online: http://www.unbc.ca/northernfire/Addictions.PDF

Brunner, L., & Suddarth, D. (1998). *Textbook of medical-surgical nursing*. Philadelphia, PA: JB Lippincott.

Bucharski, D. (2005). Aboriginal women's perspectives on "culturally appropriate" HIV counselling & testing. In *Health for all in the year 2000.* Ottawa, ON: Canadian Public Health Association.

Bucharski, D., Brockman, L., & Lambert, D. (1999). Developing culturally appropriate prenatal care models for Aboriginal women. *Canadian Journal of Human Sexuality, 8*, 151-154.

Burhansstipanov, L., & Hollow, W. (2001). Native American cultural aspects of oncology nursing care. *Seminars in Oncology Nursing, 17*(3), 206-219.

Burhansstipanov, L., Gilbert, A., LaMarca, K., & Krebs, U. (2001). An innovative path to improving cancer care in Indian country. *Public Health Reports, 116*(5), 424-433.

Cajete, G. (2000). *Native science: Natural laws of interdependence.* Santa Fe, NM: Clear Light Publishers.

Calam, B., Bass, M., & Deagle, G. (1992). Pap smear screening rates: Coverage on the southern Queen Charlotte Islands. *Canadian Family Physician, 38*, 1103-1109.

Calam, B., Norgrove, B., Brown, D., & Wilson, M. (1999). Pap screening clinics with Native women in Skidegate, Haida Gwaii: Need for innovation. *Canadian Family Physician, 45*, 355-360.

Calliou, S. (1995). Peacekeeping actions at home: A Medicine Wheel model for a peacekeeping pedagogy. In Marie Battiste & Jean Barman (Eds.), *First Nations education in Canada: The circle unfolds* (pp. 101-112). Vancouver, BC: UBC Press.

Calzavara, L. M., Burchell, A. N., Myers, T., Bullock, S. L., Escobar, M., & Cockerill, R. (1998). Condom use among Aboriginal people in Ontario, Canada. *International Journal of STD & AIDS 9*(5), 272-279.

Cameron, B., & King, M. (2004). *Towards improving access to health care services for urban and inner city Aboriginal peoples: A pilot project.* Edmonton, AB: The Alberta ACADRE Network.

Canadian Cancer Society. (2004). *Cervical cancer: What you need to know*. Retrieved on March 14, 2004 from www.cancer.ca

Canadian Institutes of Health Research. (2007). *CIHR guidelines for health research involving Aboriginal peoples.* Retrieved January 19, 2008, from www.cihr-irsc.gc.ca/e/documents/ethics_**Aboriginal_guidelines**_e.pdf

Canadian Population Health Initiative, Canadian Institute for Health Information. (2004). Chapter 7: Aboriginal peoples' health. In *Improving the Health of Canadians* (pp. 73-104). Ottawa, ON: Canadian Institute for Health Information.

Cardinal, L (2001). What is an Indigenous perspective? *Canadian Journal of Native Education, 25*(2), 180-182.

Carroll, D. & Benoit, C. (2001a). Aboriginal midwifery in Canada: Blending traditional and modern forms. *The Canadian Women's Health Network Magazine, 4*(3), 6-7.

Carroll, D. & Benoit, C. (2001b). Aboriginal midwifery in Canada: Ancient traditions and emerging forms. In L. Bourgeault, C. Benoit, & R. Davis-Floyd (Eds.), *Reconceiving Midwifery: New Canadian Model of Care* (pp. 263-286). Ann Arbor, MI: University of Michigan Press.

Castellano, M. (2002). *Aboriginal family trends: Extended families, nuclear families, families at the heart.* The Vanier Institute of the Family. Retrieved November 27, 2003, from http://www.vifamily.ca/library/cft/Aboriginal.html

Centre for Aboriginal Health Research and Northern Health Research Unit. (1998). *Research on HIV/AIDS in Aboriginal people: A background paper*. University of Manitoba. Winnipeg, MB: Centre for Aboriginal Health Research and Northern Health Research Unit.

Chalmers, B., & Wen, S. W. (2004). Perinatal care in Canada. *BMC Women's Health, 4*(Supplement 1), S28.

Chamberlain, M., Barclay, K., Kariminia, A., & Moyer, A. (2001). Aboriginal birth: Psychosocial or physiological safety? *Birth Issues, 10,* 81-85.

Chaudhry, M. (1998). Cancer incidence, mortality and survival among status Indians in Ontario, 1968-1991. Unpublished Master's Thesis, University of Ontario, Ottawa, ON. Retrieved on April 15, 2006 from http://www.collectionscanada.ca/obj/s4/f2/dsk1/tape11/PQDD 0001/MQ40708.pdf

Clarke, H., Joseph, R., Deschamps, M., Hislop, G., Band, P., & Atleo, R. (1998). Reducing cervical cancer among First Nations women. *The Canadian Nurse, 94*(3), 36-41.

Cohen M., & Maclean, H. (2004). Violence against Canadian women. *BMC Women's Health, 4*(Supplement1), S22. Available online: http://www.biomedcentral.com/1472-6874/4/S1/S22

Coombe, R. (1991). Objects of property and subjects of politics: Intellectual property laws and democratic dialogue. *Texas Law Review, 69,* 1853-1880.

Coughlin, S., Uhler, R., & Blackman, D. (1999). Breast and cervical cancer screening practices among American Indian and Alaska Native women in the United States, 1992-1997. *Preventative Medicine, 29*(4), 287-295.

Couzos, S., Wronski, I., Murray, R., & Cox, H. (1998). Augmentation of pap smear screening for high risk Aboriginal women: Use of a computerized process tool. *Broome Australian Family Physician, 27*(4), 272-274.

Craib, K. J. P., Spittal, P. M., Wood, E., Laliberte, N., Hogg, R. S., Li, K., Schechter, M. T., et al. (2003). Risk factors for elevated HIV incidence among Aboriginal injection drug users in Vancouver. *Canadian Medical Association Journal, 166*(7), 19-24.

Dell, D., Chen, H., Ahmad, F., & Stewart, D. (2000). Knowledge about Human Papillomavirus among adolescents. *The American College of Obstetricians and Gynecologists,* 96(5), 653-656.

Denzin, N. (2002). The practice and politics of interpretation, In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research, 2nd ed.* London, ON: Sage Publications.

Denzin, N., & Lincoln, Y. (Eds.). (2000). *Handbook of qualitative research.* Thousand Oaks, ON: Sage Publications.

Dickson, G., & Green, L. (2001). Participatory action research: Lessons learned with Aboriginal grandmothers. *Health Care for Women International, 22*(5), 471-482.

Dion Stout, M. (2005). Healthy living and Aboriginal women: The tension between hard evidence and soft logic. *Centres of Excellence for Women's Health Research Bulletin, 4*(2), 16-20.

Dion Stout, M. (1996a). *Aboriginal Canada: women and health.* Paper presented at Canada-U.S.A. Women's Health Forum: Ottawa, ON. Available online: http://www.hc-sc.gc.ca/canusa/papers/Canada/english/Indigen.htm

Dion Stout, M. (1996b). *Family violence in Aboriginal communities: The missing peace.* Ottawa, ON: The Royal Commission on Aboriginal Peoples.

Dion Stout, M. (1996c). Stopping family violence: Aboriginal communities enspirited. In J.R. Ponting (Ed.), *First Nations in Canada: Perspectives on opportunity.* Toronto, ON: McGraw-Hill Ryerson.

Dion Stout, M., & Kipling, G. (1998). *Aboriginal women in Canada: Strategic research directions for policy development.* Ottawa, ON: Status of Women Canada. Available online: http://www.swc-cfc.gc.ca/pubs/pubspr/0662634314/199803_0662634314_e.pdf

Dion Stout, M., & Kipling, G. (1999). *Aboriginal roundtable on sexual and reproductive health.* Ottawa, ON: First Nations and Inuit Health Branch. Available Online: http://www.hc-sc.gc.ca/fnihb/sppa/ppp/sexual_reproductive_health.htm

Dion Stout, M., Kipling, G., & Stout, R. (2001). *Aboriginal women's health research synthesis project: Final report.* Winnipeg, MB: Centres of Excellence for Women's Health Research Synthesis Group.

Dumont-Smith, C. (1995). *Information session proceedings: The national First Nations and Inuit working group on the non-traditional use of tobacco for medical services branch*. Ottawa, ON: Health Canada.

Edge, L., & McCallum, T. (2006). Métis identity: Sharing knowledge and healing practices at Métis Elder's gatherings. Pimatisiwin, *4*(2). Retrieved January 20, 2008 from http://www.pimatisiwin.com/Articles/4.2E_Métis_Identity.pdf

Eisner, E. (1979). *The educational imagination*. New York: Macmillan.

Elgersma, S. (2001). *Aboriginal women: A profile from the 1996 census*. Ottawa, ON: Indian and Northern Affairs Canada.

Elias, B. (2003). *The influence of the social environment on the health of Manitoba First Nations communities*. Unpublished Doctoral Dissertation, University of Manitoba, Winnipeg, MB.

Ellerby, J., Mckenzie, J., McKay, S., Gariepy, G., & Kaufert, J. (2000). Bioethics for clinicians: 18. Aboriginal cultures. *Canadian Medical Association Journal. 163*(7), 845-850.

Ermine, W. (1998/2001) "Pedagogy from the Ethos: an interview with Elder Ermine on language." In Lenore A. Stiffarm (Ed.), *As we see...Aboriginal pedagogy* (9-28). Saskatoon: University of Saskatchewan Extension Press.

Ermine, W. (1995). Aboriginal epistemology. In Marie Battiste & Jean Barman (Eds.), *First nations education in Canada: The circle unfolds* (pp. 101-112). Vancouver, BC: UBC Press.

Ermine, W., Sinclair, R., & Jeffery, B. (2004). *The ethics of research involving Indigenous peoples*. Report of the Indigenous Peoples' Health Research Centre to the Interagency Advisory Panel on Research Ethics. Saskatoon, SK: Indigenous Peoples' Health Research Centre.

Farkash, G. (2005). *Cervical cancer (PTG)*. Pan American Health Organization.

Feldmann, J., & Middleman, A. (2002). Adolescent sexuality and sexual behavior. *Current Opinion in Obstetrics and Gynecology*, *14*(5), 489-493.

Ferenczy, A., & Franco, E. (2002). Persistent Human Papillomavirus infection and cervical neoplasia. *The Lancet Oncology*, *3*(1), 11-16.

First Nations Information Governance Committee. (2004). *First Nations and Inuit regional health survey, 1997.* Ottawa, ON: Health Canada.

First Nations, Métis, Inuit Steering Committee and Working Committee. (2004). *Histories, cultures, and contemporary issues of First Nations, Métis, & Inuit peoples of Alberta.* A teacher preparation resource package for faculties of education and Alberta Learning. Edmonton, AB: Alberta Learning.

Fletcher, C. (1994). *The Inuulitsivik maternity: Issues around the return of Inuit midwifery and birth of Povungnituk, Quebec.* Royal Commission on Aboriginal Peoples Report. Ottawa, ON: Ministry of Supplies and Services.

Foulks, M. (1998). The papanicolaou smear: Its impact on the promotion of women's health. *Journal of Obstetric, Gynecologic, & Neonatal Nursing, 27*(4), 367-373.

Fontaine, N. (2001) *Neither here, nor there: A reflection on Aboriginal women and identity.* Unpublished Masters Thesis. Native Studies, University of Manitoba, Winnipeg, MB.

Foxall M.J., Barron C.R., & Houfek J.F. (2001). Ethnic influences on body awareness, trait anxiety, perceived risk, and breast and gynecologic cancer screening practices. *Oncology Nursing Forum, 28*(4), 727-738.

Franco, E., Duarte-Franco, E., & Ferenczy, A. (2001). Cervical cancer: Epidemiology, prevention and the role of Human Papillomavirus infection. *Canadian Medical Association Journal, 164*(7), 1017-1025.

Giroux, J., Welty, T., Oliver, F., Kaur, J., Leonardson, G., & Cobb, N. (2000). Low national breast and cervical cancer screening rates in American Indian and Alaska Native women with diabetes. *The Journal of the American Board of Family Practice, 13*(4), 239-245.

Goudreau, G. (2006). *Exploring the connection between Aboriginal women's hand drumming and health promotion (Mino-Bimaadiziwin).* Unpublished Masters Thesis, M.S. Centre for Health Promotion Studies, University of Alberta, Edmonton, AB.

Graveline, F. J. (2000). Circle as methodology: Enacting an Aboriginal paradigm. *Qualitative Studies in Education, 13*(4), 361-370.

Graveline, F. J. (1998). *Circle works: Transforming Eurocentric consciousness.* Halifax, NS: Fernwood Publishing.

Grunfeld, E. (1997). Cervical cancer: Screening hard to reach groups. *Canadian Medical Association Journal, 157*(5), 543-545. Available online: http://www.cmaj.ca/cgi/reprint/157/5/543.pdf

Gunn Allen, P. (1986). *The sacred hoop: Recovering the feminine in American Indian traditions.* Boston, NY: Beacon Press.

Hampton, E. (1995). Towards a redefinition of Indian Education. In Marie Battiste & Jean Barman (Eds.), *First Nations education in Canada: The circle unfolds* (pp. 5-46). Vancouver, BC: UBC Press.

Hankins, C., Lamont, J., & Handley, M. (1994). Cervicovaginal screening in women with HIV infection: A need for increased vigilance. *Canadian Medical Association Journal, 150*(5), 681-686.

Hankins, C., Hum, L., Tran, T., Laberge, C., Lapointe, N., & O'Shaughnessy, M. (1997). *Low HIV prevalence among childbearing women of Aboriginal origin. AIDS,* 11, 9457-947.

Hart-Wasekeesikaw F. (1996). *First Nations people's perspectives and experiences with cancer.* Unpublished Master's Thesis, University of Manitoba, Winnipeg, MB.

Healey, S. (2000). *Human Papillomavirus Infection and Cervical Dysplasia in Nunavut.* Kingston, ON, Queen's University.

Healey, S., Aronson, K., Mao, Y., Schlecht, N., Mery, L., & Ferenczy, A. (2001). Oncogenic Human Papillomavirus infection and cervical lesions in Aboriginal women of Nunavut, Canada. *Sexually Transmitted Diseases*, *28*(12): 694-700. Available Online: http://upload.mcgill.ca/cancerepi/STD-28-694.pdf

Health and Welfare Canada. (1996). *Aboriginal health in Canada.* Ottawa, ON: Author.

Health Canada. (2005). *The health of Aboriginal women.* Available at: http://www.hc-sc.gc.ca/english/women/facts_issues/facts_aborig.htm

Health Canada. (2004). Cervical cancer. Available online: http://www.hc-gc.ca/hppb/ahi/cervicalcancer/index.html

Health Canada. (2002). *Cervical cancer screening in Canada: 1998 surveillance report.* Minister of Public Works and Government Services Canada: Ottawa: ON.

Health Canada. (2001). *Organized breast cancer screening programs in Canada 1997–1998 report.* Ottawa: Minister of Public Works and Government Services.

Health Canada. (1999). *A second diagnostic on the health of First Nations and Inuit people in Canada.* Retrieved November, 1999 from http://www.hc-sc.gc.ca/fnihb/cp/publications/second_diagnostic_fni.htm

Health Canada. (1998). *1998 vital statistics of the Saskatchewan registered Indian population.* Health Canada, Planning and Evaluation Unit, Saskatchewan Region, Medical Services Branch.

Health Canada, First Nations & Inuit Health Branch. (2002). *A statistical profile on the health of First Nations in Canada.* Available online: http://www.hc-sc.gc.ca/fnih-spni/pubs/gen/2003_stat_profil/index_e.html

Health Canada, Health Canada-1: Disease Surveillance On-line. Available online: http://www.hc-sc.gc.ca/pphb-dgspsp/dsol-smed/index.html

Health Canada, Health Canada-2: Reproductive Health Division. Available online: http://www.hc-sc.gc.ca/pphb-dgspsp/rhs-ssg/phic-ispc/index.html

Health Services Utilization and Research Commission. (1997). *A comprehensive approach to cervical cancer screening*. Regina, Sask: Author.

Henderson, J. (2000). Postcolonial ghost dancing: Diagnosing European colonialism. In M Battiste (Ed.). *Reclaiming Indigenous voice and vision* (pp. 57-76). Vancouver, BC: UBC Press.

Hislop, T., Clarke, H., Deschamps, M., Joseph, R., Band, P., Smith, J., Le, N., & Atleo, R. (1996). Cervical cytology screening: How can we improve the rates among First Nations women in urban British Columbia? *Canadian Family Physician,* (42), 1701-1708.

Hodge, F., Fredericksm L., & Rodriguez, B. (1996). American Indian women's talking circle. Paper presented at the Native American Cancer Conference III: Risk Factors, Outreach and Intervention Strategies, Centre for American Indian Research and Education; Berkeley: CA, June 16-19, 1995.

Hoffman-Goetz, L., Friedman, D. B., & Clarke, J. N. (2005). HIV/AIDS risk factors as portrayed in mass media targeting First Nations, Métis, and Inuit peoples of Canada. *Journal of Health Communication, 10*(145).

Human Resources Development Canada & Statistics Canada. (1997). *The 1996 national longitudinal survey of children and youth cycle 2.* Ottawa: ON.

Humphery K., (2001). Dirty questions: Indigenous health and 'Western research.' *Australian and New Zealand Journal of Public Health,* 25(3), 197-202.

Im, S., & Monk, B. (2002). New developments in the treatment of invasive cervical cancer. *Obstetrics and Gynecology Clinics in North America,* 29, 659-672.

Indian and Northern Affairs Canada. (1997). *Implications of First Nations demography.* Ottawa, ON: Minister of Public Works and Government Services of Canada.

Johnston, G., Boyd, C., & MacIsaac, M. (2005). Community-based cultural predictors of pap smear screening in Nova Scotia. *Canadian Journal of Public Health, 95*(2), 95-98.

Jolly, A. (1993). *The epidemiology of Neisseria Gonorrhoea and Chlamydia Trachomatis genital infection and their sequelae.* Unpublished Master's Thesis, M.SC., University of Manitoba, Winnipeg, MB.

Jones, D. (2004). Pregnant Aboriginals more likely to be HIV-positive. *Canadian Medical Association Journal,* 171, 559-55a.

Kahnawake Schools Diabetes Prevention Project. (1996). *Kahnawake Schools code of ethics.* Kahnawake: Kahnawake Schools.

Kattampallil, J., Mathew, R., Zardawi, I., & Rode, J. (2001). Mucocutaneous cancer and Human Papillomavirus in the top end of Australia. *Pathology International, 51*(12), A7.

Kaufert, P., & O'Neil, J. (1988a). *The politics of obstetric care: The Inuit experience.* Department of Community Health Services. Winnipeg, MB: University of Manitoba.

Kaufert, P., & O'Neil, J. (1988b). *Obstetric care in the Keewatin: Changes in the place of birth 1971-1985.* Oulu, Finland: Nordic Council for Arctic Medical Research.

Kaufert, P., & O'Neil, J. D. (1990). Cooptation and control: The reconstruction of Inuit birth. *Medical Anthropology Quarterly,* 4, 427-442.

Kaur, J. (1996). The potential impact of cancer survivors on Native American cancer prevention and treatment. *Cancer,* 78, 1578-81.

Kavanagh, K., Absalom, K., Beil, W., & Schliessmann, L. (1999). Connecting and becoming culturally competent: A Lakota example. *Advances in Nursing Science, 21*(3), 9-31.

Kenny, C. (2002). *North American Indian, Métis and Inuit Women speak about culture, education and work.* Ottawa, ON: Status of Women Canada.

Kirkness, V., & Barnhardt, R. (1991). First Nations and higher education: The four R's-respect, relevance, reciprocity, responsibility. *Journal of American Indian Education, 30*(3), 1-15.

Kjaer, S., & Nielsen, N. (1996). Cancer of the female genital tract in Circumpolar Inuit. *Academic Oncology, 35*(5), 581-587.

Knockwood, I. (1992). *Out of the depths: The experience of Mi'kmaw children at the Indian Residential School at Shubenacadie, Nova Scotia.* Lockenport, NS: Roseway Publishing.

Lanier, P., Kelly, J., & Holck, P. (1999). Pap prevalence and cervical cancer prevention among Alaska Native women. *Health Care for Women International, 20*(5), 471-486.

Lanier, P., & Kelly, J. (1999). Knowledge, attitudes, and behaviour of Alaska Native Women regarding cervical and breast cancer. In Diane Weiner (Ed.) *Preventing and controlling cancer in North America: A cross-cultural perspective.* Westport: Praeger.

LaRocque, E. (1993). Violence in Aboriginal communities. In *The path to healing: Report of the national round table on Aboriginal health and social issues* (pp. 72-89). Vancouver, BC: Royal Commission on Aboriginal Peoples.

Lauver, D., & Rubin, M. (1991). Women's concerns about abnormal papanicolaou test results. *Journal of Obstetric, Gynecologic, and Neonatal Nursing, 20*(2), 154-9.

Lawrence, B. (1999). *'Real' Indians and others: Mixed-race urban Native people, the Indian Act, and the rebuilding of Indigenous nations.* Unpublished Doctoral Dissertation, Department of Sociology and Equity Studies, Ontario Institute for Studies in Education, Toronto, ON.

Leininger, M. (1995). *Transcultural nursing: Concepts, theories, research, and practice* (2nd ed.). New York: McGraw-Hill.

Letendre, A. (2002). Aboriginal traditional medicine: Where does it fit? *Crossing Boundaries – An Interdisciplinary Journal, 1*(2): Available online: http://www.ualberta.ca/GSA/ejournal/vol01n02/v01n02_07.pdf

Letendre, A. (2005). Sexual health practices among First Nations youth: Understanding the sexual health needs and potential concerns of First Nations youth. Unpublished manuscript of First Nations Regional Longitudinal Health Survey (RHS) 2002/03. First Nations Centre: Ottawa, ON.

Little Bear, L. (2000). *Jagged worldviews colliding,* In Marie Battiste (Ed.) Reclaiming Indigenous voice and vision. UBC Press: University of British Columbia.

Lockwood-Rayermann, S. (2004). Characteristics of participation in cervical cancer screening. *Cancer Nursing, 27*(5), 353-363.

Loppie, C. (2004). *Grandmothers' voices: Mi'kmaq women and menopause.* Unpublished Doctoral Dissertation, Interdisciplinary PhD Programme, Dalhousie University, Halifax, NS.

Lonky, N. (2002). Reducing death from cervical cancer: Examining the prevention paradigms. *Obstetrics and Gynecology Clinics,* (29)4. Available online: http://home.mdconsult.com.login.ezproxy.library.ualberta.ca/das/article/body/45916937-

Lytwyn, A., & Sellors, J. (1997). Sexually transmitted Human Papillomaviruses: Current concepts and control issues. *Canadian Journal of Human Sexuality, 6*(2).

Mandelblatt, J., Lawrence, W., & Gaffakin, L. (2001). Costs and benefits of different strategies to screen for cervical cancer in less-developed countries. *Journal of the National Cancer Institute, 94*(19), 1469-1483.

Maracle, L. (1993). Racism, sexism and patriarchy. In H. Bannerji (Ed.), *Returning the gaze: Essays on racism, feminism and politics* (pp. 148-158). Toronto, ON: Sister Vision, Black Women and Women of Colour Press.

Marsden, N., & Newmann, S. (2001). *The Aboriginal female condom pilot project: A report on the experiences of Aboriginal women living in two BC communities with the female condom: Report BC Aboriginal AIDS awareness program.* BC Centre for Disease Control, Healing Our Spirit BC Aboriginal HIV/AIDS Society. Available online: http://www.linkup-connexion.ca/catalog/prodimages/053102030335_121.pdf

Martens, P. (1997). Prenatal infant feeding intent and perceived social support for breastfeeding in Manitoba First Nations communities: A role for health care providers. *International Journal of Circumpolar Health*, 56, 104-120.

Martens, P. (2002). Increasing breastfeeding initiation and duration at a community level: An evaluation of Sagkeeng First Nation's community health nurse and peer counsellor programs. *Journal of Human Lactation*, 18, 236-246.

Martin, K. (2002). *Ways of knowing, ways of being, ways of doing; Developing a theoretical framework and methods for Indigenous re-search and Indigenist research*. Unpublished manuscript.

Martin, B., Smith, W., Orr, P., & Guijon, F. (1995). Investigation and management of intraepithelial neoplasia in Canadian Inuit: Enhancing access to care. *Arctic Medical Research*, 54(Suppl 1), 117-121.

Masuzumi, B., & Quirk, S. (1995). A participatory research process for Dene or Métis communities: Exploring community-based research concerns for Aboriginal Northerners. *International Workshop on Ethical Issues in Health Research among Circumpolar Indigenous Populations.* Inuvik, NWT: Canadian Society for Circumpolar Health.

Mathison, S. (1998). Why triangulate? *Educational Researcher.* 13-17.

McGillivray, A., & Comaskey, B. (1999). *Black eyes all of the time: Intimate violence, Aboriginal women, and the justice system.* Toronto, ON: University of Toronto Press.

McKay, A. (2000). Common questions about sexual health education. *The Canadian Journal of Human Sexualtiy*, *9*(2), 129-137.

McKechnie, J. (1997). *A profile of the Métis of Alberta*. Edmonton, AB: Métis Nation of Alberta.

McMichael, C., Kirk, M., Manderson, L., Hoban, E., & Potts, H. (2000). Indigenous women's perceptions of breast cancer diagnosis and treatment in Queensland. *Australia New Zealand Journal of Public Health, 24*(5), 515-519.

MD Consult. (2005). Clinical topic tours: Cervical cancer. Available online: http://home.mdconsult.com.login.ezproxy.library.ualberta.ca/das/news/body/1/ctt/0/6454

Meleis, A., & Im, E. (1999). Transcending marginalization in knowledge development. *Nursing Inquiry*, *6*(2), 94-102.

Meyer, M. (2003). Hawaiian hermeneutics and the triangulation of meaning: Gross, subtle, causal. *Canadian Journal of Native Education.* ProQuest Education Journals, 249-255.

Meyer, M. A. (2001). Our own liberation: Reflections on Hawaiian epistemology. *The Contemporary Pacific*: University of Hawaii Press, 123-148.

Meyer, M. (1998). Native Hawaiian epistemology: Exploring Hawaiian views of knowledge. *Cultural Survival Quarterly.* Spring 1998, 38-40.

Miles, M., & Huberman, A. (1984). *Qualitative data analysis*. Newbury Park, CA: Sage Publications.

Mill, J. (1996). *HIV infection in Aboriginal Women.* Unpublished Masters Thesis, M.N. -- University of Alberta, Edmonton, AB.

Mill, J. (1997). HIV risk behaviors become survival techniques for Aboriginal women. *Western Journal of Nursing Research*, 19, 466-489.

Miller, J. (1996). *Shingwauk's vision: A history of Native residential schools*. Toronto, ON: University of Toronto Press.

Mitchell, M., & Franklin, A. (2005). *When you don't know the language, listen to the silence: A historical overview of Native Indian women in BC.*

Moffatt, P. (2004). Colonization: A health determinant of pregnant Dogrib women. *Journal of Transcultural Nursing,* 15, 323-330.

Molodysky, E., & Bridges-Web, C. (1996). Sampling techniques for cervical cancer prevention. *Australian Family Physician, 25*(11), 1731-3.

National Aboriginal Consultation Project. (2000). *Sacred lives: Canadian Aboriginal children and youth speak out about sexual exploitation.* Vancouver: BC.

National Aboriginal Health Organization. (2008). *An overview of traditional knowledge and medicine and Public Health in Canada.* Ottawa: Author.

National Aboriginal Health Organization. (2005a). *A strategic framework to increase the participation of First Nations, Inuit and Métis peoples in health careers.*

National Aboriginal Health Organization. (2005b). *Aboriginal women and girl's health roundtable.* Available online: http://www.naho.ca/inuit/english/documents/AWGHRoundtableReport.pdf

National Aboriginal Health Organization. (2005c). *First Nations Regional Longitudinal Health Survey (RHS) 2002/03: The peoples' report.* First Nations Centre: Ottawa, ON. Available online: http://www.naho.ca/FirstNation/English/Regional_health.php

National Aboriginal Health Organization. (2002). *Governance of research involving human subjects: Research brief.* Ottawa, ON: National Aboriginal Health Organization.

National Cancer Institute. (2005). Cervical cancer (PDQ*): Screening. Health professional version. Retrieved May, 2007, from http://www.cancer.gov/cancertropics/pdq/screening/cervical/healthprofesional

National Cancer Institute of Canada. (2001). Canadian cancer statistics 2001: Toronto, ON.

Navon, L. (1999). Cultural views of cancer around the world. *Cancer Nursing, 22*(1), 39-45.

Neihardt, J. G. (1932/1959). *Black Elk speaks: Being the life of a holy man of the Oglala Sioux.* New York: Simon & Schuster.

Neron, C. (2000). HIV, sexual violence and Aboriginal women. *Native Social Work Journal*, 3, 57-72.

Newhouse, D. (1998). Magic and joy: Traditional Aboriginal views of human sexuality. *The Canadian Journal of Human Sexuality*, *7*(2), 183-187.

New Zealand Nursing. (1987). Women's experiences of cervical screening part 1 AND part 2. *New Zealand Nursing Journal*, *80*(9 & 10), pp. 19-21, 25-26.

Ng, E., Wilkins, R., Fung Kee Fung, M., & Berthelot, J. (2004). Cervical cancer mortality by neighbourhood income in urban Canada from 1971 to 1996. *Canadian Medical Association Journal, 170*(10), 1545-1549.

Nunez, A. (2000). Transforming cultural competence into cross-cultural efficacy in women's health education. *Academic Medicine*, 75, 1071-1080.

NWT Breast Cancer Working Group. (1997). *Breast cancer in the NWT: The voice of survivors: Summary report.* Yellowknife, NT: Status of Women Council of the NWT.

Ontario Federation of Indian Friendship Centres. (2002a). Aboriginal approaches to Fetal Alcohol Syndrome/Effects. Toronto, ON: Ontario Federation of Indian Friendship Centres.

Ontario Federation of Indian Friendship Centres. (2002b). *Tenuous connections: Urban Aboriginal youth, sexual health and pregnancy.* Toronto, ON: Ontario Federation of Indian Friendship Centres.

Orians C., Erb J., Kenyon K., Lantz P., Liebow E., Joe J., & Burhansstipanov L. (2004). Public education strategies for delivering breast and cervical cancer screening in American Indians and Alaska Native populations. *J Public Health Managed Practice, 10*(1), 46-53.

Paasche-Orlow M. (2004). The ethics of cultural competence. *Academic Medicine*, 79, 347-350.

Pan American Health Organization. (2000). *Promotion of sexual health: Recommendations for action.* Available online: http://www.sieccan.org/pdf/antigua_2.pdf

Pauktuutit Inuit Women's Association of Canada. (2002). Inuit women's health: A call for commitment. *Network: Canadian Women's Health*, *4*(5).

Pauktuutit Inuit Women's Association (1999). *Part 6 - Sexually Transmitted Diseases and HIV: A series on HIV/AIDS for Inuit communities*. Ottawa, ON: Pauktuutit Inuit Women's Association. Available online: http://pauktuutit.ca/hiv/hiv-part6.pdf

Permanent Forum on Indigenous Peoples. (2003).

Population Reference Bureau. (2004). *Preventing cervical cancer worldwide*. Alliance for Cervical Cancer Prevention.

Razack, S. (2000). Gendered racial violence and specialized justice: The murder of Pamela George. *Canadian Journal of Law and Society*, 15, 91-130.

Razack, S. (1998). Looking White people in the eye: Gender, race, and culture. *Courtrooms and classrooms*. Toronto, ON: University of Toronto Press.

Razack, S. (1994). What is to be gained by looking White people in the eye? Culture, race, and gender in cases of sexual violence. *Signs: Journal of Women in Culture and Society*, 19, 894-923.

Reading, J. (1999). The tobacco report. In *First Nations and Inuit Regional Health Survey: National report 1999.* Ottawa: First Nations and Inuit Regional Health Survey National Steering Committee (pp. 87–136).

Reading, J., & Nowgesic, E. (2002). Improving the health of future generations: The Canadian Institutes of Health Research Institute of Aboriginal People's Health. *American Journal of Public Health, 92*(9), 1396-1400.

Reath, J., & Usherwood, T. (1998). Improving cervical screening in a remote Aboriginal community. *Australia and New Zealand Journal of Public Health, 22*(6), 659-663.

Reeves, (2007). *The impact of post-colonial Euro-Christian culture on the sexual identity and practices of Canadian Aboriginal women.* A paper presented at the "Sex and Sexuality Conference, June, 2007, Salsberg, Austria. Retrieved on March 13, 2008, from http://www.inter-disciplinary.net/ptb/persons/pas/pas4/Reeves-paper.pdf

Reynolds-Turton, C. (1997). Ways of knowing about health: An Aboriginal perspective, *Advanced Nursing Science, 19*(3), 28-36.

Roberts, R. (2005). *Stories of cancer among the Woodland Cree of Northern Saskatchewan.* Unpublished Doctoral Dissertation (PhD), University of Saskatchewan; Regina, SK.

Rohan, T., Burk, R., & Franco, E. (2003). Toward a reduction of the global burden of cervical cancer. *American Journal Obstetrical Gynecology*, *189*(4), 37-39.

Ronson, J., & Russell, H. (2003). *A review of the literature on community cancer control in rural and northern communities.* The Steering Committee of 6th National Summit on Community Cancer Control: Cancer Control in Rural and Northern Communities, Thunder Bay: ON.

Roos, L., Traverse, D., & Turner, D. (1999). Delivering prevention: the role of public programs in delivering care to high-risk populations. *Medical Care*, *37*(6 Suppl): JS264-78

Roper, J., & Shapira, J. (2000). *Ethnography in nursing research.* Walnut Creek, CA: Atlantic Press.

Rosenberg, T., & Martel, S. (1998). Cancer trends from 1972-1991 for registered Indians living on Manitoba reserves. *International Journal of Circumpolar Health, 57*(Suppl 1), 391-398.

Royal Commission on Aboriginal Peoples. (1996a). *People to people, nation to nation: Highlights from the report of the Royal Commission on Aboriginal Peoples.* Ottawa, ON: Minister of Supply and Services Canada. Available online: http://www.ainc-inac.gc.ca/ch/rcap/rpt/lk_e.html

Royal Commission on Aboriginal Peoples (1996b). *People to people, nation to nation: Report of the Royal Commission on Aboriginal Peoples. Volume 3: Gathering strength*. Ottawa, ON: Minister of Supply and Services Canada. Available Online: http://www.ainc-inac.gc.ca/ch/rcap/sg/sim3_e.html

Royal Commission on Aboriginal Peoples (1993). *Ethical guidelines for research.* Available online at: http://www.pre.ethics.gc.ca/english/pdf/RCAP_Guidelines_1993.pdf

Royal Thai College of Obstetricians and Gynecologists & Corporation Cervical Cancer Prevention Group. (2003). Safety, acceptability, and feasibility of a single-visit approach to cervical cancer prevention in rural Thailand: A demonstration Project. *The Lancet, 361*(9360), 814-820.

Said, E. (1992). *Culture and imperialism.* Cambridge: MASS.: Harvard University Press.

Salmon Kaur, J. (1999) Native women and cancer. *Health Care for Women International, 20*(5), 445-453.

Sankaranarayanan, R., Rajkumar, R., & Theresa, R. (2004). Initial results from a randomized trial of cervical visual screening in rural South India. *International Journal of Cancer, 109*(3), 461-467.

Saskatoon Aboriginal Women's Health Research Committee. (2004). *Ethical guidelines for Aboriginal women's health research.* Saskatoon Aboriginal Women's Health Research Committee: Prairie Women's Health Centre of Excellence.

Saskatoon Health Unit. (1995). *Our health circle: The Grandmother's health assessment report.* Saskatoon, SK: The Older Native Women's Health Project, Saskatoon Community Clinic.

Saskatchewan Women's Secretariat. (1999). *Profile of Aboriginal women in Saskatchewan.* Regina, SK: Saskatchewan; Women's Secretariat. Available online: http://www.swo.gov.sk.ca/D057-ABW.pdf

Scott, K. (1997). Indigenous Canadians. In *Canadian profile 1997: Alcohol, tobacco and other drugs.* Ottawa: Canadian Centre on Substance Abuse.

Seppa, N. (2002). Virus stopper. *Science News, 162*(21), 1-2.

Ship, S. (2000). It's hard to be a woman!" First Nations women living with HIV/AIDS. *Native Social Work Journal*, 3, 73-89.

Ship, S. J., & Norton, L. (2001). HIV/AIDS and Aboriginal women in Canada. *Canadian Woman Studies*, 21, 25.

Ship, S., & Norton, L. (1998). *Triple jeopardy: The dynamic of gender, race and class discrimination, Aboriginal women and HIV/AIDS.* Kahnawake, Quebec: The National Indian and Inuit Community Health Representatives Organization.

Ship, S., Norton, L., Sterling, D., & Roussil, A. (1999). *Keepers of the Earth: Women, health and HIV/AIDS*. Kahnawake, QC: National Indian and Inuit Community Health Representatives Organization.

Sierra-Torres, C., Tyring, S., & Au, W. (2003). Risk contribution of sexual behaviour and cigarette smoking to cervical neoplasia. *International Journal of Gynecological Cancer, 13*(5), 617-625.

Smith, L. (1999). *Decolonizing methodologies: Research and Indigenous peoples.* London & New York: Zed Books/Dunedin, NZ: University of Otago Press.

Society of Obstetricians and Gynaecologists of Canada. (2001). *A guide for health care professionals working with Aboriginal peoples.*

Sohan, K., Wiggins, R., & Soothill, P. (1999). Cervical physiology in pregnancy and labour. *Fetal and Maternal Medicine Review,* 11, 135-141.

Solomon, T. (1998). *The psycho-social correlates of cervical cancer screening among American Indian women*. Unpublished Doctoral Dissertation, University of Texas, Texas.

Solomon, T., & Gottlieb, N. (1999). Measures of American Indian traditionality and its relationship to cervical cancer screening. *Health Care for Women International, 20*(5), 493-405.

Southwest Foundation for Biomedical Research. (2006). Physiology & Medicine. Retrieved August 13, 2006, from http://www.sfbr.org/pages/physiology_index.php

Stairs, A. (1995). Learning processes and teaching roles in Native education: Cultural base and cultural brokerage In Marie Battiste & Jean Barman (Eds.), *First Nations education in Canada: The circle unfolds* (pp. 139-156). Vancouver, BC: UBC Press.

Statistics Canada. (2006). Catalogue 97-558-xcb2006013 Retrieved from http://www.statcan.ca/

Statistics Canada. (2005). *National Longitudinal Survey of Children and Youth - Cycle 5.* Retrieved November, 2005, from http://www.statcan.ca/cgibin/imdb/p2SV.pl?Function=getSurvey&SDDS=4450&lang=en&db=IMDB&dbg=f&adm=8&dis=2#1

Statistics Canada. (2003). *Aboriginal peoples of Canada: A demographic profile, 2001 census*. Retrieved November, 2003, from http://www.statcan.ca/english/IPS/Data/96F0030XIE2001007.htm

Statistics Canada. (2002a). *Health of the off-reserve Aboriginal population, 2000/01*. The Daily Catalogue, 11-001E.

Statistics Canada. (2002b). *Report on the demographic situation in Canada*. Ottawa: Statistics Canada. Catalogue No. 91-209-XPE.

Statistics Canada. (1996). Census – Aboriginal tables. Available online: http://www.statcan.ca/english/census96/jan13/nalis9.htm

Statistics Canada. (1995a). *Women in Canada: A statistical report*. 3rd Edition, Ottawa: ON.

Statistics Canada. (1991). *1991 Aboriginal peoples survey: Diagnostic on the health of First Nations and Inuit people.* Ottawa: Statistics Canada. Catalogue No. 89-535.

Status of Women Canada. (2000). *Aboriginal women's roundtable on gender equality*. Ottawa, ON: Status of Women Canada. Available online: http://www.swc-cfc.gc.ca/pubs/abwomenroundtable/section3_e.html

Steed, H. (2008). HPV infections: Prevalence, prognosis, and prevention. *Cancer Care 2008: Bringing Communities of Practice Together*. The Alberta Cancer Board, Edmonton, Alberta.

Steenbeek, A. (2004). Empowering health promotion: A holistic approach in preventing sexually transmitted infections among First Nations and Inuit adolescents in Canada. *Journal of Holistic Nursing, 22*(3), 254-266.

Steier, F. (1991). Reflexivity and methodology: An ecological constructionism. In Frederick Steier (Ed.) Research and reflexivity (pp. 163-185). London, Eng: Sage Publications.

Steinhauer, E. (2002). Thoughts on an Indigenous research methodology. *Canadian Journal of Native Education, 26*(2), 69-81.

Steven, D., Fitch, M., Dhaliwal, H., Kirk-Gardner, R., Sevean, P., & Jamieson, J. (2004). Knowledge, attitudes, beliefs, and practices regarding breast and cervical cancer screening in selected ethnocultural groups in Northwestern Ontario. *Oncology Nursing Forum, 31*(2), 305-311.

Strickland, C., Chrisman, N., Yallup, M., Powell, K., & Squeoch, M. (1996). Walking the journey of womanhood: Yakama Indian women and papanicolaou (PAP) test screening. *Public Health Nursing, 13*(2), 141-150.

Tafoya, T. (1995). Finding harmony: Balancing traditional values with western science in therapy. *Canadian Journal of Native Education,* Vol. 21(Supplemental): p. 55-60.

Tafoya, T. (2005). Paper presented at National Aboriginal Health Organization Bi-Annual Conference, October 5-8, 2005, Vancouver: BC.

Tait, C. (2000). *A study of the service needs of pregnant addicted women in Manitoba.* Winnipeg, MB: Prairie Women's Health Centre of Excellence.

Tanner Spence, M. (1996). Sexually transmitted diseases in Aboriginal women. *Aboriginal Nurse*, 11, 30-32.

The Aboriginal Healing Foundation. (2003). *Aboriginal people, resilience and the Residential School Legacy*. Available online: http://www.ahf.ca/newsite/english/pdf/resilience.pdf

The Aboriginal Healing Foundation. (2004). *Historic trauma and Aboriginal healing.* Available online: http://www.ahf.ca/newsite/english/pdf/historic_trauma.pdf

The Aboriginal Nurse. (2002a). *Educating children and youth about sexuality.* Available online: http://www.findarticles.com/p/articles/mi_200201/ai_9056304/print

The Aboriginal Nurse. (2002b). *Teen pregnancy*. Available online: http://www.findarticles.com/p/articles/mi_qa3911/is_200201/ai_n9056290/print

Thomas D. (2002) Evaluating the cultural appropriateness of service delivery in multi-ethnic communities. *Evaluation Journal of Australia, 2*(2), 50-56.

Tiffen J., & Mahon S.M. (2006). Cervical cancer: What should we tell women about screening? *Clinical Journal of Oncology Nursing,10*(4), 527-531.

Tonita J., & Alvi R. (2004). *Saskatchewan cancer control report 2004: Profiling cancer in regional health authorities*. Regina Saskatchewan Cancer Agency.

Turtle Island Native Network (2003). *Preventing youth suicide in First Nations.* Available online: http://www.turtleisland.org/discussion/viewtopic.php?t=481

U.S. Preventive Services Task Force. (2003) Screening for cervical cancer: Recommendations and rationale. *American Family Physician, 67*(8), 1759-1767.

Van Kirk, S. (1980). *Many tender ties: Women in fur-trade society, 1670-1780.* Stillwater, OK: University of Oklahoma Press.

Van Manen, M. (1991/1997). *Researching lived experience: A human science for an action sensitive pedagogy.* London, ON: The Althouse Press.

Vukic, A., & Keddy, B. (2002). Northern nursing practice in a primary health care setting. *Journal of Advanced Nursing, 40*(5), 542-548.

Waldrum, J., Herring, D., & Young, T. (1995). Chapter 4: New epidemics in the twentieth century. *Aboriginal health in Canada: Historical, cultural, and epidemiological perspectives.* Toronto: University of Toronto Press Inc.

Weber, A., Tyndall, M., Spittal, P., Li, K., Coulter, S., & O'Shaughnessy, M. (2003). High pregnancy rates and reproductive health indicators among female injection-drug users in Vancouver, Canada. *The European Journal of Contraception and Reproductive Health Care*, 8, 52-58.

Weber-Pillwax, C. (2005). CURA grant application - *Healing through language and culture: Research with Aboriginal peoples of North Western Canada.*

Weber-Pillwax, C. (2004). Indigenous researchers and Indigenous research methods: Cultural influences or cultural determinants of research methods. *Pimatisiwin, 26*(1), 77-90.

Weber-Pillwax, C. (2003). *Identity formation and consciousness with reference to Northern Alberta Cree and Métis Indigenous peoples.* Unpublished Doctoral Dissertation. First Nations Education, Department of Educational Policy Studies, University of Alberta, Edmonton, AB.

Weber-Pillwax, C. (2001). What is Indigenous research? *Canadian Journal of Native Education,* 25, 166-174.

Weber-Pillwax, C. (1999). Indigenous research methodology: Exploratory discussion of an elusive subject. *Journal of Educational Thought, 33*(1), 31-45.

Weber-Pillwax, C., Louis, C., & Letendre, A. (2008). *Research in support of local/global thinkers: Removing the boarders around education and health in Aboriginal communities – Strengthening research capacity and promoting positive health outcomes through research community membership.* Paper presented at CCSE Conference, June 2-5, 2008, University of British Columbia, Vancouver, BC.

Wilson, S. (2003). *Research is a ceremony: Articulating an Indigenous research paradigm.* Unpublished Doctoral Dissertation. School of Humanities, Communications, and Social Sciences, Monash University, Melbourne, Australia.

Wilson, S. (2001). What is an Indigenous research methodology? *Canadian Journal of Native Education,* 25, 175-179

Wilson, T. (2002). *Onion Lake First Nations women: Knowledge, attitudes and health beliefs of cervical cancer and cervical cancer screening.* Unpublished Masters Thesis, (MN), University of Alberta, Edmonton, AB.

Wilson, S., & Wilson, P. (2000). Circles in the classroom. *Canadian Social Studies, 32*(2), 11-12.

World Health Organization. (2004). *Changing history.* Author. Available online: http://www.globalhealth.gov/worldhealthstatistics.shtml

World Health Organization. (2002). *Cervical cancer screening in developing countries: Report of a WHO consultation.* Author.

Young, T. (1994). *The health of Native Americans.* New York: Oxford University Press.

Young, T., Kilewer, E., & Blanchard, J. (2000). Monitoring disease burden and preventive behavior with data linkage: Cervical cancer among Aboriginal people in Manitoba, Canada. *American Journal of Public Health, 90*(9), 1466-1468.

Young, T., McNicol, P., & Beauvais, J. (1997). Factors associated with Human Papillomavirus infection detected by polymerase chain reaction among urban Canadian Aboriginal and non-Aboriginal women. *Sexually Transmitted Diseases*, 24, 293-298.

Zellerer, E. (2004). Aboriginal women's struggles for justice in Canada. In S. Pickering & C. Lambert (Eds.), *Global issues, women and justice*. Sydney, Australia: Sydney Institute of Criminology.

Zellerer, E. (1999). Restorative justice in Indigenous communities: Critical issues in confronting violence against Women. *International Review of Victimology*, 6, 345-358.

Zellerer, E. (1996). *Violence against Aboriginal women*. Ottawa, ON: Royal Commission on Aboriginal Peoples.

# Appendices

# APPENDIX A: INFORMATION LETTER FOR ABORIGINAL FEMALE COMMUNITY MEMBERS

| | | |
|---|---|---|
| Title of Study | **Aboriginal Female Sexual Health in a Context of Cervical Cancer & Cervical Cytology Screening** | |
| Investigators | Angeline Letendre, RN, PhD$_c$<br>Faculty of Nursing<br>University of Alberta<br>Phone: 961-4164 | Brenda L. Cameron, RN, PhD<br>Associate Professor and Co-investigator (ACADRE)<br>Faculty of Nursing<br>University of Alberta<br>Phone: 492-6412 |
| | Malcolm King, PhD<br>Professor & Principal Investigator of Aboriginal Capacity Development and Research Environments (ACADRE) Program<br>Faculty of Medicine<br>University of Alberta<br>Phone: 492 1827 | |

**Principal Investigator:** Angeline Letendre (780) 961-4164

**Purpose of the Research Study**

The purpose of this study is to learn about Aboriginal women's experiences with cervical cancer.

My name is Angeline Letendre. I am Aboriginal. I am also a nurse. This study is part of my university degree. We know that Aboriginal women get cervical cancer more than other women. We also know that Aboriginal women die more from cervical cancer. Cervical cancer is a health issue that is very personal. I want to learn how to treat Aboriginal women who have had cervical cancer. I want to learn how to teach Aboriginal women about cervical cancer. This can lead to health care programs that are culturally safe for Aboriginal women. This can also lead to better health policies for Aboriginal women and communities.

Aboriginal Elders, traditional teachers, and knowledge keepers will assist in the study. These Elders and teachers are known in their communities to have special knowledge of their culture. They will guide the questions that are asked in the study. They will also guide how we use the information that is gathered in the study. This will also help to make sure that we understand the information in a proper way. This study will interview six or eight Aboriginal women from different communities. All of the women will be over the age of 18. These women will work with me in the study.

## Procedure

You will be interviewed about your experience with cervical cancer. This interview will be taped. This will include when you learned that you had cervical cancer. It will include how the disease was treated. It may include any treatment you get now for the disease. You are being asked to share personal stories about this disease. You may be asked to talk about how this has affected your sexual health and overall health. In about two weeks, you will get a typed copy of the interview. This will include any translations from Cree to English. This copy will be in the form of a story. You will then be asked to look at the story. You will be asked about the correctness of the story. Your story will then be used to form one single larger story. This larger story will include all the stories from all the women interviewed about cervical cancer.

The Elders, traditional teachers, knowledge keepers, and I will look at the larger story. We will look at the larger story to see how Aboriginal woman experience cervical cancer. We will also look at the larger story to see how Aboriginal culture is revealed in the cervical cancer experiences of Aboriginal women. We will not identify any of the women who were interviewed. We will not identify their families or communities who might be included in the stories. We will not change these stories. As a group, we will choose parts of the larger story to present to the communities who were involved in the study. The stories that people share might include things about their sexual history. They might involve past sexual abuse in childhood. If so, the researcher can arrange for counselling.

## Possible Benefits and Risks

There are benefits to being in this study. You may learn more about cervical cancer. You may learn more about how to prevent cervical cancer. The results of this study may also help community members to learn about cervical cancer and the prevention of cervical cancer. This study may also help health care providers. This study will help them to see why cervical cancer and the prevention of cervical cancer among Aboriginal women need special knowledge of our culture and traditions. This can lead to special health services for Aboriginal women and communities.

Your well being is important. If you want to talk then someone will be available for counselling.

## Remuneration

You are expected to give your time and energy to this study. I believe that it is important to also give something back to the community members. I will provide a monetary gift for your time and energy.

**Privacy**
Your name and anything that you say will not appear in any report about this study. You will be given a code name and only the code name will appear with what you say. I will keep your consent form in a locked cabinet that is separate from the tapes and typed copy of what you told me. Only members of my research committee and me will be able to read the typed copies of what you have said. I will keep the tapes and typed copies of what you said in a safe place for seven years. Then I will destroy both the tapes and the typed copies of what you said.

The interview and typed copy of the interview will be private between you and me. This information will not be shared with anyone outside my research committee.

The typed copy of what you said will be used to form a story. This story will use only code names. The story will not name you or any members of your family and community. The Elders, traditional teachers, and knowledge holders will only see what you have said in the form of a story or as part of the larger story. This story will only use the code name that you have been given. When the written stories are completed that information will be included in my dissertation. In the future, if anyone wants to do more analysis with this information, they have to get ethics approval from the university.

Freedom to Withdraw
You do not have to answer any questions or discuss anything that you do not want to. You are free to withdraw from the study at any time. You do not have to give any reasons for withdrawing. You also have the right to refuse to answer any questions. If at any time, you want to turn off the tape-recorder you may. There will be no consequences if you refuse to answer any questions. There will be no consequences if you wish to turn off the tape-recorder.

Please call Angeline Letendre at (780) 961-4164 if you have any questions or concerns. You can also call the research supervisors Dr Brenda Cameron (492-6412) or Dr Malcolm King (492-1827). If you have any concerns regarding this research study please contact Dr. M.E. Horsburgh, Dean of the Faculty of Nursing at (780) 492-6236.

## APPENDIX B: CONSENT FORM – ABORIGINAL FEMALE COMMUNITY MEMBERS

| | |
|---|---|
| Title of Project: | **Aboriginal Female Sexual Health in a Context of Cervical Cancer and Cervical Cytology Screening** |
| Title of Study: | **Aboriginal Female Sexual Health in a Context of Cervical Cancer & Cervical Cytology Screening** |

Investigators

Angeline Letendre, RN, PhD$_c$
Faculty of Nursing
University of Alberta
Phone: 961-4164

Brenda L. Cameron, RN, PhD
Associate Professor and Co-investigator (ACADRE)
Faculty of Nursing
University of Alberta
Phone: 492-6412

Malcolm King, PhD
Professor & Principal Investigator of Aboriginal Capacity Development and Research Environments (ACADRE) Program
Faculty of Medicine
University of Alberta
Phone: 492 1827

**Principal Investigator(s): Angeline Letendre (780) 961-4164**

Part 2 (to be completed by the research subject):

| | | |
|---|---|---|
| **Do you understand that you have been asked to be in a research study?** | **Yes** | **No** |
| **Have you read and received a copy of the attached Information Sheet?** | **Yes** | **No** |
| **Do you understand the benefits and risks involved in taking part in this research study?** | **Yes** | **No** |
| **Have you had an opportunity to ask questions and discuss this study?** | **Yes** | **No** |
| **Do you understand that you are free to refuse to participate or withdraw from the study at any time without having to give a reason?** | **Yes** | **No** |
| **Has the issue of confidentiality been explained to you? Do you understand who will have access to your information?** | **Yes** | **No** |

**This study was explained to me by:** ______________________________

**I agree to take part in this study** **Yes** **No**

______________________ ______________ ______________________

**Signature of Research Participant** **Date** **Witness**

______________________ ______________________

**Printed Name** **Printed Name**

**I believe that the person signing this form understands what is involved in this study and agrees to participate.**

______________________ ______________

**Signature of Investigator or Designee** **Date**

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH SUBJECT.

# APPENDIX C: INFORMATION LETTER FOR MEMBERS OF ELDER GROUP

| | | |
|---|---|---|
| Title of Study | **Aboriginal Female Sexual Health in a Context of Cervical Cancer & Cervical Cytology Screening** | |
| Investigators | Angeline Letendre, RN, PhD$_c$<br>Faculty of Nursing<br>University of Alberta<br>Phone: 961-4164 | Brenda L. Cameron, RN, PhD<br>Associate Professor and Co-investigator (ACADRE)<br>Faculty of Nursing<br>University of Alberta<br>Phone: 492-6412 |
| | Malcolm King, PhD<br>Professor & Principal Investigator of Aboriginal Capacity Development and Research Environments (ACADRE) Program<br>Faculty of Medicine<br>University of Alberta<br>Phone: 492 1827 | |

**Principal Investigator:** **Angeline Letendre** **(780) 961-4164**

## Purpose of the Research Study

The purpose of this study is to learn about Aboriginal women's experiences with cervical cancer. I also want to learn how culture affects the sexual health of Aboriginal women.

My name is Angeline Letendre. I am Aboriginal. I am also a nurse. This study is part of my university degree. We know that Aboriginal women get cervical cancer more than other women. We also know that Aboriginal women die more from cervical cancer. Cervical cancer is a health issue that is very personal. I want to learn how to treat Aboriginal women who have had cervical cancer. I want to learn how to teach Aboriginal women about cervical cancer. This can lead to health care programs that are culturally safe for Aboriginal women. This can also lead to better health policies for Aboriginal women and communities.

I am using Aboriginal research to look at this health issue. As an Elder, traditional teacher, or knowledge keeper, you will assist in the research. You will guide the collecting of data. You will guide the interpreting of data. Your guidance will also help to make sure that we look at the data in the proper way. This research will interview six Aboriginal women from different communities. All of the women will be over the age of

18. These women will work with the researcher. These women may also work with the Elders and traditional teachers.

## Procedure

This study has three parts.

You will be interviewed about your culture in part one of the study. This interview will be audio and video recorded. This interview will be confidential between you and me. You will be asked questions about the sexual health of Aboriginal women. You will be asked to share cultural stories and teachings about the sexual health of Aboriginal women. After two weeks, you will get a typed copy of the interview. This copy will include any translations from Cree into English. You will then be asked to look at the correctness of the copy. This copy will then be used to guide the questions in part two of the study. Part two of the study asks Aboriginal women about their experiences with cervical cancer. These interviews are then made into one large story for part three of the study. The stories do not name any of the women who were interviewed. These stories do not name their families or communities.

In part three of the study, Aboriginal Elders, traditional teachers, and knowledge keepers and I will then look at the stories of these women. We will look at these stories to better understand how Aboriginal women experience cervical cancer. We will also be looking to see how culture is reflected in the stories of these Aboriginal women. We will not name any of the Aboriginal women. We will not name their families or communities. We will not change these stories. As a group, we may choose parts of the larger story to take to the communities who were involved in the research.

## Possible Benefits and Risks

There are benefits to being in this study. First, you will learn about cervical cancer and the prevention of cervical cancer. You may also gain knowledge in sharing your cultural teachings. The results of this study may help communities to better understand this health issue. A last benefit is that this study may help health care workers to understand why the sexual health of Aboriginal women requires special knowledge of our culture and traditions. This can lead to more culturally safe sexual health education and services for Aboriginal women and communities.

Your trust in me is important. If you decide that some of the information or teachings being discussed should remain confidential, then the researcher will exclude them from any part of the study including final written results or publications.

Your wellbeing is also important. If you want to stop the interview at any time, then the researcher will abide by your wishes. If you want to stop being involved in the research at any time, then the researcher will abide by your wishes.

**Remuneration**
You are expected to give your time and energy to this study. I believe it is important to give something back to community members for their time, teaching, and sharing. The researcher will provide monetary gifts in exchange for your time and energy.

**Confidentiality**
The interviews will be confidential between you and me. This information will not be shared with anyone outside the Elder group. When the written story is completed that information will be included in my final results of the study. All the information will be kept for seven years in a locked file cabinet. My supervisors will be the only other people who may read the transcripts. After seven years the tapes and notes will be destroyed. In the future, if anyone wants to do more analysis with this information, they have to get ethics approval from the university.

**Freedom to Withdraw from the Study**
You are free to withdraw from the study at any time. You do not have to give any reasons to withdraw from the study. You also have the right to refuse to answer any questions. If at anytime, you want to turn off the tape-recorder you may. There will be no consequences if you refuse to answer any questions. There will be no consequences if you wish to turn off the tape-recorder. If you decide not to participate in the interview and analysis process then you may still assist in presentations of the results to communities at later dates and still be involved.

Please contact Angeline Letendre at (780) 961-4164 if you have any questions or concerns.

For additional information, you can contact the research supervisors Dr Brenda Cameron (492-6412) or Dr Malcolm King (492-1827). If you have any concerns regarding this research study please contact Dr. M.E. Horsburgh, Dean of the Faculty of Nursing at (780) 492-6236.

# APPENDIX D: CONSENT FORM – MEMBERS OF ELDER GROUP

Title of Study **Aboriginal Female Sexual Health in a Context of Cervical Cancer & Cervical Cytology Screening**

Investigators

Angeline Letendre, RN, PhD$_c$
Faculty of Nursing
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Professor & Principal Investigator of
Aboriginal Capacity Development and
Research Environments (ACADRE)
Program
Faculty of Medicine
University of Alberta
Phone: 492 1827

**Principal Investigator:** **Angeline Letendre** **(780) 961-4164**

Part 2 (to be completed by the research subject):

| | | |
|---|---|---|
| **Do you understand that you have been asked to be in a research study?** | **Yes** | **No** |
| **Have you read and received a copy of the attached Information Sheet?** | **Yes** | **No** |
| **Do you understand the benefits and risks involved in taking part in this research study?** | **Yes** | **No** |
| **Have you had an opportunity to ask questions and discuss this study?** | **Yes** | **No** |
| **Do you understand that you are free to refuse to participate or withdraw from the study at any time without having to give a reason?** | **Yes** | **No** |
| **Has the issue of confidentiality been explained to you? Do you understand who will have access to your information?** | **Yes** | **No** |

This study was explained to me by: ____________________________

I agree to take part in this study Yes No

____________________________ ____________________ __________________________

**Signature of Research Participant** **Date** **Witness**

____________________________ __________________________

**Printed Name** **Printed Name**

**I believe that the person signing this form understands what is involved in this study and agrees to participate.**

____________________________ ____________________

**Signature of Investigator or Designee** **Date**

**THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH SUBJECT.**

# APPENDIX E: CONSENT FORM – MEMBERS OF ELDER GROUP FOR AUDIO/VIDEO RECORDINGS

| | | |
|---|---|---|
| Title of Study | **Aboriginal Female Sexual Health in a Context of Cervical Cancer & Cervical Cytology Screening** | |
| Investigators | Angeline Letendre, RN, PhD$_c$<br>Faculty of Nursing<br>University of Alberta<br>Phone: 961-4164 | Brenda L. Cameron, RN, PhD<br>Associate Professor and Co-investigator (ACADRE)<br>Faculty of Nursing<br>University of Alberta<br>Phone: 492-6412 |
| | Malcolm King, PhD<br>Professor & Principal Investigator of Aboriginal Capacity Development and Research Environments (ACADRE) Program<br>Faculty of Medicine<br>University of Alberta<br>Phone: 492 1827 | |

**Principal Investigator:** **Angeline Letendre** **(780) 961-4164**

Part 3 (to be completed by the research subject):

**I have read and retained a copy of the Letter of Information and I have had any questions answered to my satisfaction:**
***Please initial:*** **_____ Yes ____ No**

**I consent to be audio-taped during this study:**
***Please initial:*** **_____ Yes ____ No**

**I give consent for transcripts associated with me to be used in the final dissertation as well as for academic publication(s) and for presentation at academic conference(s):**
***Please initial:*** **_____ Yes ____ No**

**I consent to be videotaped during this study:**
***Please initial:*** **_____ Yes ____ No**

**I give consent for clips from videotapes associated with me to be used ONLY for**
**i)presentation during the dissertation defence**
***Please initial:*** **_____ Yes ____ No**

**ii)presentation at academic conference(s)**
***Please initial:*** **_____ Yes ____ No**

**iii) presentation within Aboriginal community information sessions**
***Please initial:*** **_____ Yes ____ No**

**I consent to be photographed during this study:**
***Please initial:*** ______ **Yes** ______ **No**

**I give consent for photographs containing recognizable images of myself or other non-participants to be used ONLY for:**

**i)presentation during the dissertation defence**
***Please initial:*** ______ **Yes** ______ **No**

**ii)presentation at academic conference(s)**
***Please initial:*** ______ **Yes** ______ **No**

**iii) presentation within Aboriginal community information sessions**
***Please initial:*** ______ **Yes** ______ **No**

**I understand that my identity, as well as the identity of non-participants, will not to be revealed in written data resulting from this study unless I have requested otherwise:**
***Please initial:*** _____ **Yes** ____ **No**

**This study was explained to me by:** ______________________________

**I agree to take part in this study** **Yes** **No**

| | | |
|---|---|---|
| ______________________ | ______________ | ______________________ |
| **Signature of Research Participant** | **Date** | **Witness** |
| ______________________ | | ______________________ |
| **Printed Name** | | **Printed Name** |

**I believe that the person signing this form understands what is involved in this study and agrees to participate.**

______________________ ______________
**Signature of Investigator or Designee** **Date**

**THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH SUBJECT**

# APPENDIX F: CONFIDENTIALITY AGREEMENT FOR TRANSLATOR

Title of Study **Aboriginal Female Sexual Health in a Context of Cervical Cancer & Cervical Cytology Screening**

Investigators

Angeline Letendre, RN, PhD$_c$
Faculty of Nursing
University of Alberta
Phone: 961-4164

Brenda L. Cameron, RN, PhD
Associate Professor and Co-investigator (ACADRE)
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Malcolm King, PhD
Professor & Principal Investigator of
Aboriginal Capacity Development and
Research Environments (ACADRE)
Program
Faculty of Medicine
University of Alberta
Phone: 492 1827

Principal Investigator: Angeline Letendre
Faculty of Nursing, University of Alberta
Phone: 961-4164

**Supervisor:** Dr. Brenda Cameron, Professor
Faculty of Nursing, University of Alberta
Phone: 492-6412

I agree to protect the privacy and confidentiality of those involved in this study. I will not disclose the name or any other pertinent information that may lead to the identification of the study participants.

| | | |
|---|---|---|
| Translator Signature | Print Name | Date |
| Witness Signature | Print Name | Date |

# APPENDIX G: ABORIGINAL FEMALE CANCER SURVIVORS INTERVIEW GUIDE

**1. Basic demographic questions of age, gender, educational level.**

**2. Questions regarding health and illness:**

- **What does it mean to be healthy for you?**
- **What kind of things do you do to stay healthy?**
- **What does it mean to be sick for you?**
- **What do you do when you are sick?**
- **Who do you go see? Anybody else?**
- **What kind of things do you do to make yourself well again?**
- **What kind of things did women do in the old days to stay healthy?**
- **What did women do in the old days when they got sick?**
- **Do you still follow any of the old ways? Would you like to tell me about them?**

**3. Questions regarding cancer:**

- **Tell me about your cancer experience? Type? Age? Treatment? Current status?**
- **How did you feel when you were told you had cancer?**
- **What did you know about cancer before you got it? What did you know about this type of cancer?**
- **What do you know about cancer now?**
- **How many women do you know that have had this kind of cancer? What happened to them? Do you think there are more women getting this kind of cancer?**
- **How do you feel when you hear that a woman has this kind of cancer?**
- **Who do you talk to about your cancer illness?**
- **Do you think there was anything you could have done to prevent you from getting cancer? Was there anything you could have done to get diagnosed earlier?**
- **Are there things that can be done to prevent other women from getting this kind of cancer?**

**4. Integration of cancer in worldview:**

- **Will cancer always be a part of your life? If yes, in what way?**
- **What kinds of things do you do now to prevent getting cancer again?**
- **What has happened to the way you think of life since you had cancer?**

**Do you do different things now to stay healthy? What about when you get sick?**